The Communication of Personalised Cancer Statistics to Cancer Patients

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Abstract

The truthful and complete disclosure of cancer statistics is required by many cancer patients. However, most of the statistics provided to patients are still very general. Therefore, an interactive tool is being developed for kanker.nl that will provide personalised cancer statistics. However, the question remains of how to communicate personalised cancer statistics to cancer patients. Therefore, this study investigates how seven breast cancer and four prostate cancer patients evaluate two presentation formats, one short and concise, and one long and detailed, that communicate personalised cancer statistics. To this end, think-aloud sessions and interviews are conducted to collect the evaluations, which consist of three parts: getting started, entering data, and receiving results. In addition, general remarks are provided. Evaluations are then coded in terms of content, navigation, lay-out, feelings of the patients, preferences of the patients, and problems with the scenario. The results show that when communicating personalised cancer statistics, some parts of the tool need to be communicated briefly (i.e. introduction), and other parts at greater length (i.e., the titles of the results section). However, most of the patient preferences differ with other patients, therefore conclusions are generally unclear. Furthermore, the results indicate that receiving personalised cancer statistics can generate emotional feelings, regardless of the presentation format. Overall, structured, and patient-friendly information, without unnecessary use of technical terms, is most appreciated. The results of this study serve as a base for further developments of the tool for kanker.nl, and for further research in the field of personalised health or cancer statistics.

Keywords: communication, personalisation, cancer, statistics, patients, presentation format, evaluations, preferences

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1. Introduction

A very important, and widely recognized, component of effective supportive cancer care is that cancer patients must be provided with appropriate information (Turner et al., 2005). Upon diagnosis, a truthful and complete disclosure of cancer statistics is what many patients want and need (Fletcher, Flight, Chapman, Fennell, & Wilson, 2017). This helps to increase patients' understanding of their diagnosis, and can also increase their involvement in the shared decision-making process about treatment with their physicians (Elwyn et al., 2017). Furthermore, when patients are provided with timely and accurate information they can experience reduced fear and anxiety about their cancer and treatment (Husson, Mols, & van de Poll-Franse, 2011), as well as improvements in pain management and daily functioning (Fletcher et al., 2017).

Nowadays, health-related websites are an essential source for physicians and patients to find information about cancer (Moreno, Morales del Castillo, Porcel, & Herrera-Viedma, 2010). When patients are able to find the information they desire, this can reduce- anxiety and uncertainty (Leydon et al., 2000). However, the process of finding the correct information can be complicated, because the rapidly growing online environment lacks publishing control and the guarantee of a high-quality website (Grigoroudis, Litos, Moustakis, Politis, & Tsironis, 2008). Part of the cancer information sought by patients are statistics about their cancer. The most frequently used cancer statistics are frequency, incidence, mortality, and survival rates (Jemal et al., 2004). However, cancer statistics at present are limited for various reasons (Vromans et al., 2019). Firstly, they are general statistics and are not personalised per patient, because they are based on the statistics of current or previous cancer patients. Accordingly, it is difficult for patients to apply statistics to their personal situations (van Stam & van der Poel, 2018). Secondly, as it is challenging to maintain cancer statistics they are not always based on the latest evidence. As a consequence, these statistics may be more harmful than helpful for patients (Montori, Leblanc, Buchholz, Stilwell, & Tsapas, 2012). Thirdly, statistics can be difficult for patients to understand when they are expressed as percentages or probabilities, and the communication of these statistics is not always patient-friendly (Gigerenzer, Gaissmaier, Kurz-Mileke, Schwartz, & Woloshin, 2008).

To solve these issues, a tool is being developed to automatically generate specific personalised statistical information. The format of this tool needs to be understandable and accessible for patients (Vromans et al., 2019). Since information and communication are important factors in developing a coping strategy to deal with cancer, and because the preferred information differs per patient (Leydon et al., 2000), the personalization of cancer statistics via this tool offers a very good solution. Furthermore, according to Ingram (1984), and Kreuter et al. (2000), people may be more likely to remember information when it is tailored to their individual characteristics. Hence, when information is made more specific by considering, gender, age, cancer type, and phase of the cancer continuum, patients are more likely to remember it. In this way, the tool is designed to aid the decision-making process. Initially the tool will only be made available for the most common types of cancer: breast, prostate, and colon cancers. However, the question remains as to which communication format is the most suitable for personalised statistics.

Multiple studies focus on the communication of health statistics to patients. For example, Büchter, Fechtelpeter, Knelangen, Ehrlich, and Waltering (2014), examined the comparative effects of words and numbers in communicating the probability of adverse effects to consumers in written health information. Their findings suggest that consumer health information providers should quantify treatment effects numerically. Meanwhile, Garcia-Retamero and Cokely (2013), reviewed multiple studies that investigate the advantages of visual aids in the communication of health risks to vulnerable people. According to these studies, appropriately designed visual aids are generally highly effective, and transparent, and thus are desirable tools that improve the decision-making process, change attitudes, and reduce risky behaviour. Bolle et al. (2016), applied several categories to evaluate the user experiences of older cancer patients, cancer survivors and their partners with existing web-based health information tools. The study identified variety in the participants' preferences regarding the amount of information communicated to them in the tools, as participants appreciated detailed information while others did not.

However, to the researchers' knowledge, no existing studies focus on how to communicate *personalised* cancer statistics to cancer patients. Therefore, this study represents a first attempt to investigate the most appropriate type of communication for personalised cancer statistics. More specifically, this study investigates how two presentation formats that communicate personalised cancer statistics – one short and concise, and one long and detailed – are evaluated by breast and prostate cancer patients. The decision was made to evaluate breast and prostate cancer patients because these are the most common species of cancer in the Netherlands. Furthermore, these two patient groups also represent two different population groups, as the prostate cancer patients are all male and the breast cancer patients are almost all female, and these groups may process information differently. Furthermore, the treatment options and survival chances differ in these groups, which may also influence how these patient groups process information. This leads to the central research question for this study:

RQ: How do breast and prostate cancer patients evaluate a short and concise, and a long and detailed presentation format, which communicate various personalised cancer statistics?

To answer this research question, first, a theoretical framework is developed.

2. Theoretical Framework

2.1. Information provision and needs of cancer patients

2.1.1. General statistics. The most common cancer types in the Netherlands are breast cancer (representing 26.6% of cancer cases) for women and prostate cancer (20.8%) for men (cijfersoverkanker.nl, 2018). The incidental rates for breast- and prostate cancer are still rising; in 2000 more than 12,000 new breast cancer patients and 7,000 new prostate cancer patients were diagnosed, while in 2018 these figures rose to more than 17,000 new breast cancer patients and 12,500 new prostate cancer patients (cijfersoverkanker.nl, 2019). The survival rates for breast and prostate cancer vary because they depend on the stage of cancer. For stage I breast cancer, almost all patients are still alive after 1 year, and after 5 years 98% are still alive. In stage IV, 80% of the patients are still alive after 1 year, and after 5 years only 29% are still alive (cijfersoverkanker.nl, 2018). For stage I prostate cancer, 100% of the patients are still alive after 1 year and after 5 years. In stage IV, 90% of the patients are still alive after 1 year, and only 50% are still alive after 5 years (cijfersoverkanker.nl, 2018). Disease characteristics such as year of diagnosis and stage of cancer make a significant difference to the general incidence and survival rates. Considering that these are just two of many disease characteristics, and that every cancer patient has a different combination of characteristics, it could be questioned if these general statistics are a good source of information for patients' personal situations. However, cancer patients do have a need for cancer statistics, such as incidence, survival, and conditional survival rates, that inform them optimally about their personal situation.

2.1.2. Information needs and efforts of cancer patients. Generally, cancer patients want to receive information about their cancer (Meredith et al., 1996). According to Fletcher et al. (2017), upon diagnosis many patients need and want a truthful and complete disclosure of their cancer statistics, which, according to Leydon et al. (2000), might help to increase their understanding of their diagnosis and to help them cope with cancer. This is in line with the findings of Fallowfield, Ford, and Lewis (1995), who determined the preferences of patients for general or more specific information with regard to their disease and treatment. Of the 101 participants, 94% wanted as much information as possible from their doctors, in both favourable and unfavourable situations. Hence, cancer patients overall have the desire to be well-informed about their diagnosis, prognosis, therapeutic options, and side-effects. However, the need for precise information varies between cancer patients (Fallowfield et al., 1995). Differences in these information needs were highlighted by Leydon et al. (2000), who explored why cancer patients do not want or seek additional information besides the information provided by their doctors, and whether this differed throughout the illness. Basic information about diagnosis and treatment was desired by all 17 patients in the study, but not all of them wanted more information at all stages in the cancer continuum. More specifically, six patients did make efforts, to get as detailed information as possible, while the other 11 patients put minimal effort into obtaining additional information. The timing of patients' desire for this information, as well as the level of detail and content they require, varies considerably, which is reflected in the effort made to obtain this information (Leydon et al., 2000). Accordingly, providing information in oncology can be very complex.

2.2. Personalisation of statistics

A number of issues are currently encountered when providing patients with cancer statistics. In sum, the information that is available on the web might be too general for patients. For example, a patient searching for the survival rate for a specific type of breast cancer usually sees a survival rate that is based on the entire group of breast cancer patients. As this quoted survival rate is the mean of the entire group, it may deviate completely from the patient's own survival rate. Furthermore, meeting the information needs of the patients is very difficult because all patients have personal preferences. However, providing them with suitable information is important, since they are involved in the decision-making process. Cancer statistics are also limited for number of reasons (Vromans et al., 2019). They are general statistics, which makes it hard to apply them to personal situations (van Stam & van der Poel, 2018). They are not always based on the most recent evidence, which might be more harmful than helpful (Montori et al., 2012). Furthermore, they can be hard to understand, and the way they are communicated can be patient-unfriendly (Gigerenzer et al., 2008).

Personalisation of cancer statistics could confront these issues. According to Bol et al. (2018, p. 373), personalisation in general, can be defined as ‘the strategic creation, modification, and adaptation of content and distribution to optimise the fit with personal characteristics, interests, preferences, communication styles, and behaviours’. In this study, personalisation of cancer statistics means that the provided statistics are more applicable to patients’ personal situations, as the statistics are based on a group with the exact same characteristics as the patients seeking information, and not on a complete group of patients. For example, a patient is 48 years old and has stage four prostate cancer with a PSA value of 19 and a Gleason score of 8. When this patient demands personalised statistics, only statistics which are based on patients with the same characteristics as this patient will be returned.

When patients receive information that is related to their personal situation, their information needs can be met more easily. Moreover, patients may also be more likely to remember information when it is tailored to their individual characteristics (Ingram, 1984; Kreuter et al., 2000). However, although it may be relevant to provide patients with their personal cancer statistics, it is not yet known how to communicate personalised statistics. To gain insight for the communication aspect, it is important to establish how patients process information when diagnosed with cancer. Furthermore, it is important to determine the most suitable presentation format, according to the literature.

2.3. Information processing in cancer

A person's cognitive capability may be affected when they are diagnosed with cancer, since comprehension and the processing of information are provisionally reduced (Kuang & Wilson, 2017).

2.3.1. Information processing. According to Baddeley (1992), the working memory is a system in the brain that oversees the information's temporary storage and manipulation, which is essential for complicated cognitive tasks. It has been established that the working memory of people requires the synchronous storage and processing of information. As the working memory resources are confined, individuals can only process a small amount of information at a time (Baddeley, 1992). These limits of the working memory highlight the importance of relieving cognitive resources of inessential processing that is caused by, for example, the ineffective design of materials. Since in healthcare situations events are generally stressful and mentally taxing for patients, it is especially important in this context to use designs that aim to free cognitive resources. The processes involved in the working memory are driven by learner goals, text factors, and other influences such as the situational context. For example, when a person receives a new diagnosis or when this person is in an emergency care situation, the stress level (i.e., the situational context) of this person is generally very high. In this case, the working memory becomes increasingly cluttered with distracting thoughts and painful symptoms may become prominent (Wilson & Wolf, 2009). Through this, information processing may become more difficult.

2.3.2. Emotion and information processing. From diagnosis onwards, the experience of breast or prostate cancer is generally extremely stressful for patients. (Ptacek, Pierce, Ptacek, & Nogel, 1999; Shapiro et al., 2001). Moreover, the way in which patients receive their diagnosis can immediately raise their stress levels, which in turn can intensify negative emotions (Gibbons, Groarke, Curtis, & Groarke, 2017). From the moment of diagnosis, patients start to experience different levels of emotional disturbance (Reyna, Nelson, Han, & Pignone, 2015) such as uncertainty, sadness, depression, shock, guilt, fear of suffering, anxiety, ambiguity, anger, and fear of death (Reyna et al., 2015; Shapiro et al., 2001). Generally, breast and prostate cancer represent an overwhelming emotional experience for patients (Lubeck et al., 1999; Shapiro et al., 2001). Negative emotional reactions can be provoked by the cancer diagnosis which can trigger a range of emotional experiences (Reyna et al., 2015; Shapiro et al., 2001). Subsequently, patients and their relatives may enter a state of intense uncertainty. Patients' thinking and information-processing capabilities to deal with cancer can be influenced by this specific cancer-related emotional distress (Bowen et al., 1999), as well as their skills for coping (Brandão, Tavares, Schulz, & Matos, 2016), and their decision-making processes during cancer treatment (Reyna et al., 2015). Emotional adjustment throughout the cancer continuum can be improved as the provided information more closely matches patients' preferences (Ankem, 2006). Subsequently, this may have a positive impact on the information processing phase.

2.3.3. Cognitive load and information processing. On the basis of its constrained capacity, the working memory permits people to focus on prioritised aspects of the materials that they encounter, to monitor the ongoing understanding of important information, and to ignore residual elements in order to avoid information overload (Baddeley, 1992; Wilson & Wolf, 2009). When attempting to teach individuals new information, the constraints of the working memory underline the importance of reducing unneccessary cognitive demands. According to the cognitive load theory of Sweller (1994), the mental requirements placed on people by educational materials can arise as a result of factors intrinsic to the contained message (such as the material's conceptual difficulty), or by way of extrinsic cognitive demands related to the way in which the message is designed (such as the format, font size, or word choice of the message), (Sweller, 1994; Sweller, van Merrienboer, & Paas, 1998).

Cognitive load can also be relevant in that people must be active participants in the learning process, and some form of mental investment is needed to achieve a deeper comprehension. Besides intrinsic load and germane load, there is also excessive extrinsic load. Intrinsic load is inherent to conceptual content, and germane load is favourable to peoples' eventual understanding and application of information. However, excessive extrinsic load (such as emotions and stress) can impede the capability to master of the content by hindering the working memory with unnecessary processing (Wilson & Wolf, 2009).

While peoples' social and cognitive skills, as well as their motivation, can differ, the way in which health information is generally communicated makes it very hard for all patients to understand and retain (Wilson & Wolf, 2009). This may be due to factors that influence peoples' cognitive capability, such as the difficulty of the information itself (intrinsic) or an incorrect way of presenting the information (extrinsic), but can result from situational factors such as negative emotions and stress (extrinsic). One, or a combination of these factors can result in cognitive overload.

Since cognitive overload can have consequences for the understanding and decision-making processes of patients, according to Reyna et al. (2015), it is important to consider cognitive load theory when designing health information tools for cancer patients.

In sum, the factors discussed above are interrelated. The difficulty of the material, an incorrect way of presenting the material, and emotions and stress can result in cognitive overload, which hinders individuals' information processing. This lack of knowing and understanding material and the presence of negative emotions are not optimal for the decision-making process in the cancer continuum. Considering this knowledge, an appropriate way of communicating material is the starting point. According to (Wilson & Wolf, 2009), the design of the materials should promote the successful encoding of information by recognising and accounting for the possibility that patients' processing abilities might be hindered or limited. However, the question remains of what this ideal format for communicating personalised cancer statistics should look like.

2.4. The ideal presentation format

2.4.1. Most suitable presentation format according to the literature. Multiple studies focus on the communication of health information to patients. Büchter et al. (2014), reviewed the comparative effects of words and numbers in communicating the probability of adverse effects to consumers in written health information.. They found that compared to numerical information, verbal descriptors (i.e., uncommon, common, and rare) can cause overestimations of the probability of adverse effects. In contrast, numbers result in more accurate assessments and also increase the satisfaction and likelihood of medication use. Therefore, they authors suggest that consumer health information providers need to express the quantitative effect of treatment numerically.

Studies by Cepeda et al. (2008), and Chou, Hunt, Folkers, and Augustson (2011), found that the stories of cancer survivors have a positive influence on the health of listeners, as well as the health of the storytellers. In addition, these stories appear to have a positive effect on readers and listeners because this reduces feelings of isolation and fear throughout the illness (Rozmovits & Ziebland, 2004). According to Aaker and Aaker (2016), this suggests that the stories of patients appear to be more credible, authentic, and appealing in comparison with only documenting the facts.

In another study by de Wit, Das, and Vet, (2008), the authors compared the effects of narrative and statistical evidence in promoting the acceptance of a personal health risk. They found that perceptions of personal risk and intentions to take action were highest after the presentation of narrative evidence. They proposed that when persuading message recipients, it is more effective to present individuals with narrative evidence, because this type of message content is less subject to a defensive response than statistical evidence.

Although, these studies provide evidence that supports using a shorter numerical presentation format, or longer narrative presentation formats when communicating health information, it remains unclear which presentation format is the most suitable for communicating personalised cancer statistics.

2.4.2. Information characteristics. To make the information that will be presented more accessible and to avoid cognitive overload, some characteristics can be taken into account in both presentation formats. First of all, according to Gigerenzer et al. (2008), many patients do not understand the meaning of health statistics and/or make incorrect conclusions without noticing. This is also referred to as collective statistical illiteracy, ‘the widespread inability to understand the meaning of numbers’ (Gigerenzer et al., 2008, p. 53). When the public does not understand these numbers, they can be amenable to commercial and political manipulation of their hopes and anxieties, which subverts the goals of shared decision-making and informed consent. Statistical illiteracy is caused by intentional or unintentional nontransparent framing of information, and can have serious effects for health. To prevent this statistical illiteracy, Gigerenzer et al. (2008, p. 53) recommend to make information transparent by ‘using frequency statements instead of single-event probabilities, absolute risks instead of relative risks, mortality rates instead of survival rates, and natural frequencies instead of conditional probabilities’. However, regarding the presentation of mortality rates instead of survival rates, disagreements can be found in literature. For example, according to the study of Davey, Butow, and Armstrong (2003), patients prefer positively framed language when receiving prognostic information. This means that patients should be presented with survival probabilities and not with chances of mortality. Another study by Brooker (2007), suggests that both the mortality rate and survival rate need to be defined in order to assess the impact on the patient properly.

Secondly, the information needs to be patient-friendly, especially for older adults. It is important to write for users, and therefore technical terms and difficult language needs to be avoided (Bolle et al., 2016; Wilson & Wolf, 2009). Thirdly, regarding the amount of information, mixed findings can be seen. In a study by Bolle et al. (2016), some participants did not appreciated detailed information whereas others needed as much detail as possible. Furthermore, the possibility for patients to expand the text for certain topics as desired was greatly appreciated by all participants. As recommended by Bolle et al. (2016), large amounts of text should be avoided, and in order to give users a conscious choice of what information they would like to see, options to expand text can be created. To satisfy those users who want detailed information as well as users who want to see a limited amount of information, text can be optionally extended when more detail is preferred.

2.4.3. Lay-out- and design characteristics. When creating a presentation format for the personalised cancer statistics, some layout- and design characteristics should be taken into account to avoid hindrance when processing information. According to the study by Bolle et al. (2016), when searching for information participants often start at the centre of a webpage and do not pay attention to its structure. Therefore, navigational elements should be presented in the centre of a webpage as this helps older patients to directly make a navigational choice without being distracted. Furthermore, the participants in this study knew how to scroll up and down and they also did not mind doing so.

Meanwhile, according to Bahr and Ford (2011), and Bolle et al. (2016), the use of unexpected pop-ups is not appreciated at all. In terms of layout, according to the study by Bolle et al. (2016), and following the best practices of Wilson and Wolf (2009), to avoid cognitive load the following recommendations can be made. Using a clear, large and simple font is appreciated, as well as the use of a plain background that contrasts with the text and maximises the space as much as possible. Furthermore, supportive illustrations and graphics should only be used when they clarify the text. These recommendations can be used in the design of presentation formats for health information tools.

2.5. Background of the current study

This study is particularly important for two parties: the Netherlands Comprehensive Cancer Organisation, hereafter termed IKNL, and kanker.nl. IKNL is the quality institute for oncological and palliative research and practice, and collects relevant data on the comprehensive care process. They are able to provide medical professionals with proper information on their patients' disease status and treatments, and keep all collected data in the Netherlands Cancer Registry (NCR). Their goal is to promote better therapy and high-quality palliative care. They develop tools to support doctors in making the right decisions together with their patients. Overall, IKNL work hard to improve cancer care and palliative care (IKNL, n.d.).

Kanker.nl is the central online platform in the Netherlands that provides information about cancer to everyone who has to deal with cancer it: cancer patients, cancer survivors, and their relatives. Kanker.nl provides a variaty of reliable information about cancer. It helps cancer patients, cancer survivors, and their relatives to have a better understanding of their personal situation, and aids them in making well-considered choices. This can improve their quality of life and collaboration with practitioners (Kanker.nl, n.d.).

The site was partly an initiative of IKNL. The relation between IKNL and kanker.nl is that IKNL shares data and insights from the NCR with kanker.nl, who in turn communicate this information through their website. You may say that the shared goal of both parties is, to provide cancer patients, survivors, and relatives with the best available information about cancer, to improve the quality of life of cancer patients, and to help them make well-considered choices (Kanker.nl, n.d.). However, the statistics provided to the public by IKNL through kanker.nl are still very general. Therefore, a tool is being developed to provide personalised cancer statistics which are based on insights and data from the NCR. By making specific statistics about cancer available for patients, and personalising these statistics, patients are able to receive more precise information than what is currently available. This helps them even more to cope with their cancer and make decisions. Accordingly, launching the tool on kanker.nl will towards achieving the goal of IKNL and kanker.nl.

The goal of this study is to obtain evaluations from cancer patients of different presentation formats for the tool, since little is known about how to communicate personalised cancer statistics to patients. Therefore, the insights from this study are of great importance for the developments and launch of the tool and thereby also for IKNL and kanker.nl. In addition, the findings from this study are valuable for other research in the field of communicating personalised statistics.

3. Method

In this study, a within-subjects design was set up to investigate whether there was a difference in cancer patients' evaluations of the communication depending on the format. Within the independent variable, the communication format, two conditions were compared: communication of the information in a short and concise presentation format, and in a long and detailed format. The dependent variable in this study was the evaluation of the presentation format. The overall evaluation consisted of the evaluation of different categories within the presentation formats. The main categories were the content, the feelings of the patients, and the preferences of the patients. Additionally, the layout and the navigation through the content were categories that the study was not specifically focused on, but patients also automatically evaluated these categories. Data was gathered by conducting think-aloud sessions and interviews. This study was approved by the Ethics Review Board of Tilburg Law School (approval no. REDC 2019.44).

3.1. Participants

Two groups of patients were asked to participate in this study. The first group consisted of women who had previously been diagnosed with breast cancer, and the second group consisted of men who had previously been diagnosed with prostate cancer. The participants were recruited via employees of IKNL, who consulted the Borstkankervereniging Nederland (BVN) for breast cancer patients, and the ProstaatKankerStichting (PKS) for prostate cancer patients. The requirements for participants were a previous diagnosis of breast or prostate cancer, ability to speak the Dutch language, and knowledge of computer use. No further requirements were set. See appendix A for the invitation letter.

3.2. Material

The main goal for this study was to evaluate the communication of a tool to generate personalised cancer statistics for patients, in order to improve the tool. This tool will be able to automatically generate personalised multimodal reports of statistical cancer information, in a format that should be both understandable and accessible for patients (Vromans et al., 2019). To develop this tool, the data of millions of Dutch cancer patients was analysed. This data was sourced from the NCR, which records all new cancer diagnoses and holds information about the diagnoses, treatment, and vital status of patients. The first version of the tool will only focus on the most frequently diagnosed forms of cancer in the Netherlands: prostate, breast, and colon cancer. In addition, the tool will initially focus on three types of cancer statistics: incidence, survival, and conditional survival rates (Vromans et al., 2019). Eventually the tool will be added to the Dutch cancer website, www.kanker.nl, where general cancer statistics can already be viewed.

The development of the tool is still in the initial phase. In order to gain insights and feedback about the first ideas, look, and feel of the tool from patients and professionals in the field, some first designs have been produced (Vromans et al., 2019). Since this study mainly examines the communication aspect of this tool, and is only focused on breast and prostate cancer patients, an iteration of the designs of the developed tool was made. These designs have a medium design fidelity for different reasons. Firstly, the look and feel of kanker.nl was used, so the visual design is similar to that of the webpage. Secondly, the mock-up was made interactive so that every button is clickable and participants are able to interact with it. Thirdly, the navigation between the different screens in the mock-up was also operational. The personalised statistics displayed in the mock-up version were fictional, so they were not based on the personal situations of the participants. Instead, they were based on a patient who the participants had to imagine.

Overall, the intention was not to create a prototype that resembles the end product, but to create a mock-up that was able to obtain insights about the communication of personalised cancer statistics. Therefore, a distinction between two versions of the tool was made that represented two different ways of presenting the information. In one version the information was showed in a short and concise manner, with raw statistics and the minimum required explanation to understand the statistics. This version included clickable options to access more information and explanation when needed. In addition, all of the results were displayed at once. In the second version, the information was presented in a long and detailed manner, with more information, provided in a clearer way and with explanations about the displayed statistics in a story-like presentation style. In this version participants were also able to choose which results they wanted to see. These mock-ups were used as the stimulus for this study. Adobe Illustrator CS6 was used to create all the different screens in the mock-ups, and Invision was used to make the mock-ups interactive (https://www.invisionapp.com/).

Since the purpose of the tool is to enable the personalisation of cancer statistics, but this part could not be included in the mock-up used as the stimulus in this study, four scenarios were created. Two of the scenarios were about breast cancer patients, in which one patient had a favourable scenario and the other an unfavourable scenario. The other two scenarios were about prostate cancer patients, in which one patient again had a favourable scenario and the other an unfavourable scenario. In the favourable scenario the survival outcome was ‘good’, and in the unfavourable scenario the survival outcome was ‘bad’. This distinction between favourable and unfavourable was made to base the evaluations on both ‘better’ and ‘worse’ situations.

The tool was divided into three parts: getting started, entering data, and receiving results. The ‘getting started’ category consisted of the introduction, warning statements, and general or personalised statistics. The ‘entering data’ category consisted of personal data, and disease-related data. The ‘receiving results’ category consisted of a summary of the data, incidence rates, survival rates, figures, conditional survival rates, and an explanation of the statistics.

In Figure 1 to 14, a few examples are shown of screens from two of the eight versions of the tool, in which the long and detailed presentation format shows a favourable scenario, while the short and concise presentation format shows an unfavorable scenario. Both of the displayed examples are the formats used for breast cancer patients, in order to show the differences more clearly. The various categories (i.e., introduction, statistics question, personal data etc.) within the tool for the two formats are shown next to each other, in order to see the differences between the two versions more clearly. Other examples of screens from the other six versions (two for breast cancer and four for prostate cancer) are shown in Appendix B, to indicate important differences between the versions.

Overlevingscijfers borstkanker

De volgende pagina's geven cijfers over borstkanker. U kunt zien hoeveel mensen jaarlijks borstkanker krijgen en hoeveel mensen deze ziekte overleven. Deze statistieken geven een algemeen beeld voor de hele groep. Deze geven geen informatie over uw situatie. Uw vooruitzichten kunnen beter of slechter zijn dan de vooruitzichten voor de hele groep. Bespreek uw vooruitzichten met uw arts.

Wij vinden het belangrijk dat patiënten en naasten toegang hebben tot betrouwbare cijfers, maar alleen als iemand ook daadwerkelijk meer wil weten over cijfers. De statistische berekeningen worden gedaan met de gegevens uit de Nederlandse Kankerregistratie (NKR).

Als u vragen heeft, is het belangrijk om de betreffende pagina te printen en mee te nemen naar het ziekenhuis, zodat u de informatie kunt bespreken met uw arts.

Figure 1. Introduction: breast, long, favourable

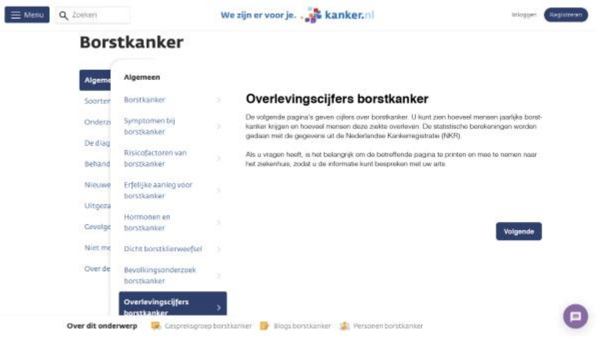

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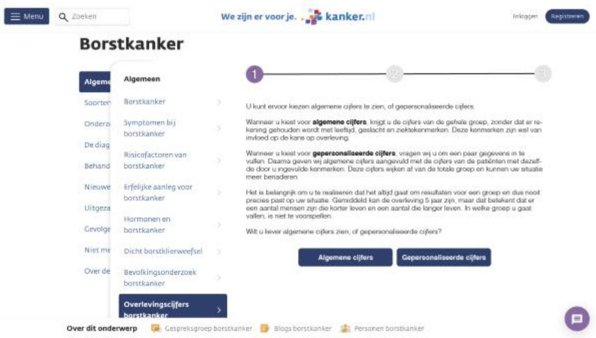
Figure 2. Introduction: breast, short, unfavourable



U kunt ervoor kiezen algemene cijfers te zien, of gepersonaliseerde cijfers.

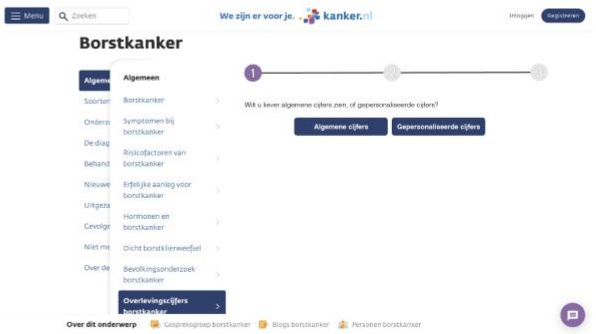
Wanneer u kiest voor **algemene cijfers**, krijgt u de cijfers van de gehele groep, zonder dat er rekening gehouden wordt met leeftijd, geslacht en ziektekenmerken. Deze kenmerken zijn wel van invloed op de kans op overleving.

Wanneer u kiest voor **gepersonaliseerde cijfers**, vragen wij u om een paar gegevens in te vullen. Daarna geven wij algemene cijfers aangevuld met de cijfers van de patiënten met dezelfde door u ingevulde kenmerken. Deze cijfers wijken af van de totale groep en kunnen uw situatie meer benaderen.

Het is belangrijk om u te realiseren dat het altijd gaat om resultaten voor een groep en dus nooit precies past op uw situatie. Gemiddeld kan de overleving 5 jaar zijn, maar dat betekent dat er een aantal mensen zijn die korter leven en een aantal die langer leven. In welke groep u gaat vallen, is niet te voorspellen.

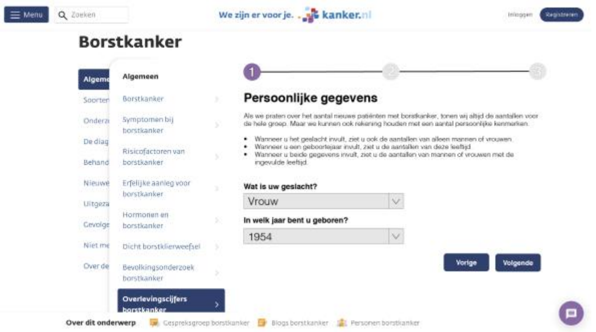
Wilt u liever algemene cijfers zien, of gepersonaliseerde cijfers?

Figure 3. Statistics question: breast, long, favourable



Wilt u liever algemene cijfers zien, of gepersonaliseerde cijfers?

Figure 4. Statistics question: breast, short, unfavourable



Persoonlijke gegevens

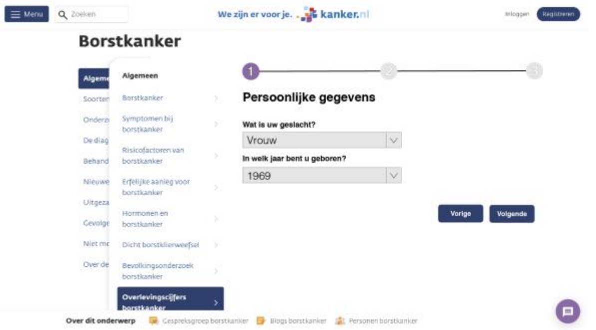
Als we praten over het aantal nieuwe patiënten met borstkanker, tonen wij altijd de aantallen voor de hele groep. Maar we kunnen ook rekening houden met een aantal persoonlijke kenmerken.

- Wanneer u het geslacht invult, ziet u ook de aantallen van alleen mannen of vrouwen.
- Wanneer u een geboortejaar invult, ziet u de aantallen van deze leeftijd.
- Wanneer u beide gegevens invult, ziet u de aantallen van mannen of vrouwen met de ingevulde leeftijd.

Wat is uw geslacht?
Vrouw

In welk jaar bent u geboren?
1954

Figure 5. Personal data: breast, long, favourable



Persoonlijke gegevens

Wat is uw geslacht?
Vrouw

In welk jaar bent u geboren?
1969

Figure 6. Personal data: breast, short, unfavourable

Gegevens over uw ziekte bij diagnose

We kunnen de cijfers nog meer op maat presenteren, wanneer u ook één of meerdere ziektekenmerken kunt invullen. Dit zijn gegevens over uw ziekte **bij diagnose**, zoals het stadium van de ziekte, en in welk jaar u de diagnose kreeg. Als u deze gegevens invult, kunnen wij overlevingscijfers tonen op basis van patiënten met ongeveer dezelfde ziektekenmerken bij diagnose. Ook nu is het belangrijk om na te denken of u wel cijfers wilt ontvangen op basis van deze gegevens. Als u bij alle kenmerken 'weet ik niet' invult, krijgt u de algemene cijfers te zien.

In welk jaar kreeg u de diagnose?
2016

Wat was het stadium van de ziekte bij diagnose?

Figure 7. Disease data: breast, long, favourable

Gegevens over uw ziekte bij diagnose

In welk jaar kreeg u de diagnose?
2015

Wat was het stadium van de ziekte bij diagnose?
Weet ik niet

Waren er uitzaaiingen gevonden bij diagnose?

Figure 8. Disease data: breast, short, unfavourable

Resultaten

Op deze pagina ziet u cijfers over borstkanker. U heeft aangegeven om gepersonaliseerde cijfers te ontvangen, zodat deze uw situatie meer benaderen.

De cijfers die wij tonen, zullen daarom gebaseerd zijn op **vrouwen** die op **65-jarige leeftijd** de diagnose borstkanker **stadium I** kregen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 9. Results, summary: breast, long, favourable

Resultaten

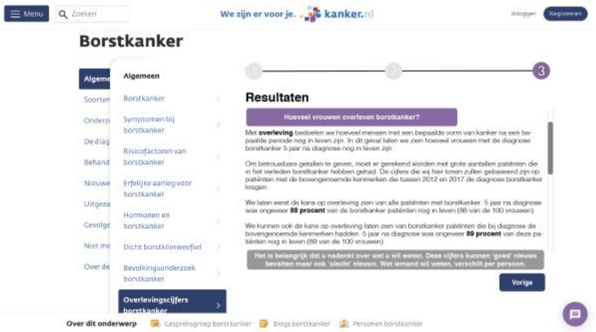
Op deze pagina ziet u cijfers over borstkanker. De cijfers die wij tonen, zijn gebaseerd op patiënten met de volgende kenmerken bij diagnose:

Geslacht: **Vrouw**
Diagnosejaar: **2015**
Uitzaaingen: **Ja, elders in het lichaam**
Geboortejaar: **1969**
Stadium: **Onbekend**

In **2015** kregen in totaal 14.597 vrouwen de diagnose borstkanker. In 2015 kregen 70 vrouwen de diagnose uitgezaaide borstkanker op 50-jarige leeftijd.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 10. Results, summary: breast, short, unfavourable



Resultaten

Met **overleving** bedoelen we hoeveel mensen met een bepaalde vorm van kanker na een bepaalde periode nog in leven zijn. In dit geval laten we zien hoeveel vrouwen met de diagnose borstkanker 5 jaar na diagnose nog in leven zijn.

Om betrouwbare getallen te geven, moet er gerekend worden met grote aantallen patiënten die in het verleden borstkanker hebben gehad. De cijfers die wij hier tonen zullen gebaseerd zijn op patiënten met de bovengenoemde kenmerken die tussen 2012 en 2017 de diagnose borstkanker kregen.

We laten eerst de kans op overleving zien van alle patiënten met borstkanker. 5 jaar na diagnose was ongeveer **88 procent** van de borstkanker patiënten nog in leven (88 van de 100 vrouwen).

We kunnen ook de kans op overleving laten zien van borstkanker patiënten die bij diagnose de bovengenoemde kenmerken hadden. 5 jaar na diagnose was ongeveer **89 procent** van deze patiënten nog in leven (89 van de 100 vrouwen).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 11. Results, survival: Breast, long, favourable.

Resultaten

Algemene cijfer: 5 jaar na diagnose was ongeveer **88 procent** van de borstkanker patiënten nog in leven (88 van de 100 vrouwen).

Gepersonaliseerde cijfer: 5 jaar na diagnose was ongeveer **38 procent** van de patiënten met bovengenoemde kenmerken nog in leven (38 van de 100 vrouwen).

Het is belangrijk om te weten dat uw vooruitzichten nog steeds beter of slechter kunnen zijn dan de vooruitzichten voor deze specifieke groep. Bespreek uw vooruitzichten met uw arts.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 12. Results, survival: Breast, short, unfavourable

Resultaten

De figuur hiernaast toont de **5-jaarsoverleving** van borstkanker patiënten met bovengenoemde kenmerken. U kunt het type figuur aanpassen naar uw wensen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 13. Results, figure 1: Breast, long, favourable

Resultaten

Van de patiënten met bovengenoemde kenmerken die 4 jaar na diagnose nog leefden, was de kans dat zij 5 jaar na diagnose nog in leven waren **gestegen van 38 procent naar 60 procent**

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Figure 14. Results, figure 1: Breast, short, unfavourable

In the scenarios, all personal characteristics, such as age and gender, and disease characteristics, such as year of diagnosis and type of cancer, were mentioned. All information that was necessary for the participants to complete the task was included in the scenarios. The patients that participated in the study were asked to complete the given tasks from the viewpoint of one of the scenarios. For ethical reasons (i.e., emotional weight of the topic) the scenarios were written as if 'Person A' needed the answer to the given question, and not the participant his or herself. The four scenarios are shown in Appendix C.

The main goal of the task given to the participants was to find personalised incidence and survival rates. Every step that the participants needed to perform, and every detail to keep in mind, was clarified in the task description, which is displayed in Appendix D.

3.3. Data collection methods

For this study, two methods were used: a think-aloud session and a semi-structured interview. According to Krahmer and Ummelen (2004), the think-aloud method can be used for three types of goals, of which this study focused on two. The first, is ‘to discover and understand general patterns of behaviour in the interaction with documents or applications, in order to create a scientific basis for designing them’ (Krahmer & Ummelen, 2004, p. 1). This study focused on the evaluation of the two different communication formats. By concentrating on general patterns in evaluating behaviour, the researcher was able to decipher if there were general routes that participants took and general interactions that participants performed with certain aspects of the format. With these behaviuoral patterns, the tool can be improved. The second goal, is ‘to test specific new documents or applications in order to troubleshoot and revise’ (Krahmer & Ummelen, 2004, p. 2). When participants evaluated the two different formats, they verbalised their positive and negative thoughts about certain aspects of the format. With this user information the formats can be revised where needed. These two goals are consistent with the goal of this study, and therefore this method was highly suitable.

Furthermore, the methodological choices were based on the theoretical framework of from Ericsson and Simon (1980), in which the subjects continuously verbalise their thoughts and the experimenter (mostly) listens. However, since this framework for thinking aloud is unnatural, the framework of Ericson and Simon is combined with the framework of Boren and Ramey (2000). In the latter framework, the subjects are not the only ones verbalising, but the experimenter is also contributes to the dialogue. One of the advantages of this framework is that the subjects are prompted by the experimenter to keep verbalising their thoughts in a natural and proactive way. However, this technique was only applied when the researchers thought it was necessary to maintain the flow of the sessions and to obtain better or more data. When it was not necessary, the experimenter remained silent and only listened, in order to avoid interfering with the subjects' cognitive processes. Therefore, it is a combination of both frameworks.

During the think-aloud sessions, participants used a particular stimulus, for a given task while they verbalised their thoughts. From these thoughts, the researcher could determine how the participants were interacting with the mock-ups, and the reasons for their behaviour. In addition, thinking aloud showed how participants interpreted interface items. With these insights into the participants' thought processes, misunderstandings were identified and can be used in the next development phase of the tool were these aspects can be revised. An advantage of this method is the abundance of qualitative data that can collected from a relatively small group of participants (Nielsen, 1994), another reason for the use of method of this method.

The interviews were semi-structured and designed to capture insights about how the patients evaluated the communication types on multiple categories. Furthermore, they obtained insights about the patients' preferences for communicating personalised cancer statistics. An advantage of using a semi-structured interviews is that the researcher can go into specific directions of the research question while creating the possibility for the participants to contribute new meanings and insights to the study (Galletta, 2013). This flexibility was appropriate for this study because it creates opportunities for evaluations to unfold, which the researcher is able to anticipate.

3.4. Procedure

All participants contributed to this study voluntarily. IKNL contacted the patients. The full research procedure took place at the homes of the patients or at the offices of IKNL in Amsterdam, Eindhoven, Rotterdam, and Utrecht.

First of all, a short introduction took place. In this introduction the participants were explained how the structure of the process looked like. Besides, the aim of the session was briefly explained. More specifically, the participants were told that the think-aloud session was meant to gain knowledge about how cancer patients evaluate the communication format of specific cancer information. To reassure the participants, they were told that there was no wrong way in doing the tasks and that there were no stupid or wrong answers during the interview. Furthermore, the participants were told that they could drop out of the study when desired without any consequences. To make sure this was handled in the correct way, participants were asked to sign a consent form. The elaborated version of the introduction is displayed in Appendix E, and the consent form is displayed in Appendix F.

Next, the researcher asked for some background information. The form with background questions is showed in Appendix G. After that, the researcher explained the think-aloud method. First, the researcher illustrated the means of a think-aloud session by showing how to think aloud by searching for a word in a dictionary. After that, the participants experienced how to think aloud, by practicing with the online version of the Tower of Hanoi (Krahmer & Ummelen, 2004). They were asked to make this exercise on https://www.mathsisfun.com/games/towerofhanoi.html, with the intention to focus on practicing with thinking out loud, and not necessarily on solving the exercise. This practicing exercise was continued until the participants convinced the researchers of understanding the think-aloud method. Subsequently, the real data gathering began.

The participants received the task description, and a favourable or unfavourable scenario about a breast or prostate cancer patient, dependent on which diagnosis they have had in the past. The order in which the scenarios were given was randomized. After reading the scenario and task description, participants had a moment to ask questions if aspects were unclear, if needed, these were explained to them. After a clear understanding of both the scenario and the task description, the participants started with the task, the voice recording started, and note-taking began. To enhance thinking aloud, several questions were asked by the researchers: ‘How would you start’, ‘What are you thinking right now?’, ‘Why did you do that?’, ‘Can you elaborate on that?’. Besides, reassuring sounds were made to enhance thinking aloud: ‘uhuh’ (Nielsen, 1994). During the tasks, the researchers only answered questions from the participants if the questions were so urgent that the ignorance of them would stop the process. In these cases, the researcher tried to give a counter-question such as, ‘What will happen if you do it?’ (Nielsen, 1994). If the participants stopped verbalising their thoughts, the researchers interrupted with a question like ‘What are you thinking right now?’. The participants were asked to express their thoughts and opinions about the different categories for evaluation.

Since the researchers wanted to know how the participants thought about both the communication formats, the participants needed to do the think-aloud session with both the different formats. The order in which the two presentation formats were presented was randomised. The sessions were divided by a break in which the participants could ask questions and in which the researcher could elaborate on the verbalised thoughts of the participants. Subsequently to the think-aloud sessions, an interview started with questions about both the presentation formats. With the interview the researcher aimed to gain knowledge about why the participants evaluated the communication formats the way they did. The example questions for the semi-structured interviews are showed in Appendix H.

After the interview, the researchers asked if the participants had any contributions to, or questions about the topic. This was recorded as well. At the end of the session, the researchers gave a debriefing about the study (see Appendix I). Subsequently, the researchers thanked the participants for their help.

3.5. Analysis

All think-aloud observations and statements from the interviews were transcribed and coded by one researcher. The coding procedure was based on the one used by Bolle et al. (2016). Two rounds of coding took place. In the first round basic codes (category, perspective, and scale) were given and in the second round more specificity was provided for some categories when this facilitated analysis.

The evaluation of the presentation formats was analysed on the basis of the three different parts of the tool: getting started, entering data, and receiving results. General remarks were also provided, which consisted of general feedback, intention to use, and general experience. All data was analysed from six perspectives: content of the information, navigation within the format, lay-out of the format, feeling of the patient (i.e., if the patient was aware of a specific feeling), preference of the patient, and problems with the scenario. Regarding the content of the information, the navigation within the format, the layout of the format, the feeling of the patients, and problems with scenario, it was also coded whether the think-aloud observations and interview statements of the patients were negative, neutral, or positive.

During the first coding round these categories, perspectives, and scales were initially used as the basic codes. Some subcategories were created during the second round of coding when too many observations and statements were present within the basic codes. For example, in the category ‘figures’, subcategories such as ‘icon array’, ‘pie chart’, ‘bar chart’, and ‘line graph’ were added, which facilitated the analysis phase. The code tree is shown in Figure 15.

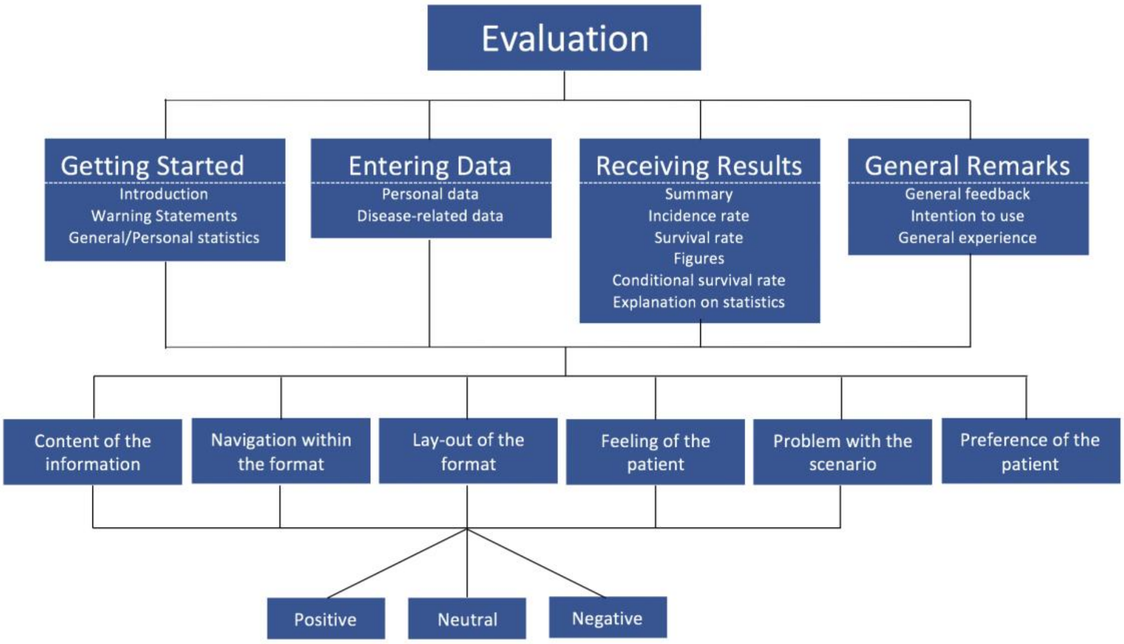


Figure 15. Code tree.

4. Results

4.1. Participants

Participants were seven breast cancer patients, hereafter termed BCPs, and four prostate cancer patients, hereafter termed PCPs. These two groups were analysed separately from each other. The mean age of the BCP group was 51 (*SD* = 7.51). The BCPs their characteristics are listed in Table 1. The mean age of the PCP group was 66.25 (*SD* = 3.63). The characteristics of the PCP group are listed in Table 2. An overview of all the characteristics from both groups with total values per characteristic, is listed in Table 3.

Table 1.

Breast cancer patients' characteristics

Patients ID	B1	B2	B3	B4	B5	B6	B7
Age[a]	54	60	45	36	50	53	59
Year of diagnosis	2016	2013	2013	2016	2016	2017	2009
Education	S. School[b]	College	University	S. School[b]	University	College	College
Employment status	Employed	Unemp.[c]	Employed	Unemp.[c]	Employed	Employed	Employed
Marital status	No partner	Married	No partner	Married	Married	No partner	No partner
Children	No	Yes NLW[d]	No	Yes LW[e]	Yes LW[e]	Yes NLW[d]	No

[a] Age at time of study.
[b] Secondary school.
[c] Unemployed.
[d] Yes, not living with.
[e] Yes, living with.

Table 2.

Prostate cancer patients' characteristics

Patients ID	P1	P2	P3	P4
Age[a]	68	68	60	69
Year of diagnosis	2011	2015	2018	2014
Education	University	College	S. School[b]	S. School[b]
Employment status	Retired	Retired	Retired	Retired
Marital status	Married	Married	No partner	Married
Children	Yes NLW	Yes NLW[c]	No	Yes NLW[c]

[a] Age at time of study.
[b] Secondary school.
[c] Yes, not living with.

Table 3.

Overview patients' characteristics

	Breast cancer patients (n=7) n (%)	Prostate cancer patients (n=4) n (%)
Male	0 (0%)	4 (100%)
Female	7 (100%)	
Mean Age (SD)	51 (7.51)	66.25 (3.63)
Age range	36-60	60-69
Year of diagnosis range	2009-2017	2011-2018
Education		
Secondary school	2 (28.6%)	2 (50%)
College	3 (42.9%)	1 (25%)
University	2 (28.6%)	1 (25%)
Employment status		
Employed	5 (71.4%)	0 (0%)
Unemployed	2 (28.6%)	0(0%)
Retired	0 (0%)	4 (100%)
Marital status		
Married	3 (42.9%)	3(75%)
No partner	4 (57.1%)	1(25%)
Children		
Yes, living with	2 (28.6%)	0 (0%)
Yes, not living with	2 (28.6%)	3 (75%)
No	3 (42.9%)	1 (25%)

4.2. Evaluations of the presentation formats

In general, the BCP group used more words during the evaluation of the tool (*M* = 5,499, *SD* = 811.71), than the PCP group (*M* = 3,881, *SD* = 1101.54). However, regarding the interview sessions the PCP group used more words (*M* = 2,549, *SD* = 545.44), than the BCP group (*M* = 2,001, *SD* = 388.11). When comparing the used words within the four different versions of the mock-up in general, most words were used for the long and detailed presentation format with the favourable scenario (*M* = 751.83, *SD* = 558.88). Also, when looking at both patient groups separately, for both the PCP group (*M* = 727, *SD* = 126), as the BCP group (*M* = 764.25, *SD* = 678.32), most words were used in this version during the evaluations. However, the short and concise format with the favourable scenario was evaluated with the least words in general (*M* = 532.60, *SD* = 332). Although, the PCP group used the least words for the short and concise format with the unfavourable scenario (*M* = 571, *SD* = 84), whereas the BCP group used the least words for the short and concise format with the unfavourable scenario (*M* = 444.67, *SD* = 204.86). An overview of the used words from all participants, is listed in Table 4.

Both the short and concise, and long and detailed versions of the tool were evaluated on different categories during the think-aloud sessions and interviews. Each relevant statement or sentence that was provided during the sessions was coded per category, and together these codes and statements form the coding scheme (see Figure 15.). Analyses were then carried out per category and group; the BCP group, and the PCP group, were analysed separately. The next section presents the results per category, starting with the results from the BCP group, followed by the PCP group.

Table 4.

Overview of used words from all participants

Format and scenario	Long and favourable[a]	Long and unfavourable[a]	Short and favourable[a]	Short and unfavourable[a]	Interview	Total
Prostate cancer						
P1		1,039	1,093		3,402	5,534
P2	853			655	2,633	4,141
P3	601			487	2,171	3,259
P4		364	236		1,990	2,590
Total	1,454	1,403	1,329	1,142	10,196	15,524
Mean	727	701.5	664.5	571	2,549	3,881
(*SD*)	(126)	(337.5)	(428.5)	(84)	(545.44)	(1101.54)
Breast cancer						
B1		455	461		2,332	3,248
B2	492			772	1,430	2,694
B3	1931			689	2,022	4,642
B4		401	186		1,487	2,074
B5		679	687		2,566	3,932
B6	367			349	1,983	2,699
B7	267			256	2,187	2,707
Total	3,057	1,535	1,334	2,066	14,007	21,996
Mean	764.25	511.67	444.67	516,5	2,001	5,499
(*SD*)	(678.32)	(120.36)	(204.86)	(218.49)	(388.11)	(811.71)
Overall total						
Total	4,511	2938	2,663	3,208	24,203	37,520
Mean	751.83	587.60	532.60	534.67	2,200.27	3,410.91
(*SD*)	(558.88)	(250.80)	(332)	(186.65)	(523)	(993.38)

[a] Format and scenario used in think-aloud method

4.2.1. Part I – getting started.

4.2.1.1. Introduction. In the BCP group, the introduction was mainly evaluated on its content. Overall, all BCPs agreed during the interviews that the purpose of the tool became clear in the introduction, for both formats (n=7; 100%). Furthermore, four BCPs agreed that the content was informative enough in both versions to proceed to the next page (57.1%). One BCP (14.3%) confessed that she did not read all of the content but scanned it as she wanted to see the statistics. However, two BCPs (28.6%) had some feedback regarding the content, which mostly related to the vague formulation of some words and sentences such as 'the entire group' or 'doctor'. For example, one BCP commented, '*I have lost track of what the 'entire group' means, I am dropping a little here' (B5).* Additionally, some BCPs noticed that they preferred the short and concise version as the content was shorter in this version (n=3; 42.9%). For example, one BCP said, *'if people search for survival rates, they are very focused on seeing these statistics, so I would prefer to see a short introduction' (B5).* Only one BCP (14.3%) mentioned that she was already aware of a 'negative' feeling while reading the introduction. She mentioned, *'I realised something like, there is a chance that it will be bad news' (B4).*

In the PCP group, the introduction was also mainly evaluated on the content. Overall, all PCPs agreed that in both formats the purpose of the tool became clear from the content (n=4; 100%). Furthermore, all PCPs also agreed that the content was informative enough in both versions to proceed to the next page (n=4; 100%). The only remark was from one PCP (25%) who stated one sentence in the long and detailed version was unnecessary. He said *'in this part, it is important that patients and relatives have access to reliable statistics, yeah, that is a bit unnecessary for me' (P2).* Additionally, another PCP (n=1; 25%) mentioned during the interview that he preferred the content in the introduction to be as short as possible *(P4).*

4.2.1.2. Warning statements. Within the BCP group, most participants mentioned during the interviews that it was clear why the warnings were shown to them (n=6; 85.7%). Only one BCP did not mention if the warnings were clear to her, since again she only scanned the content. Overall, BCPs were very positive about the warnings. For example, one mentioned *'now I first see all sorts of useful information to keep in mind' (B4)*. Additionally, all participants agreed that it was a good idea to show these kinds of warning statements (n=7; 100%). However, two BCPs (28.6%) had some feedback about the formulation of the sentences in the content. For example, the terms 'good news' and 'bad news' were not appreciated. One BCP commented *'this is very weird in my opinion; these numbers may contain good news but also bad news, so I think that is quite a statement' (B5)*. Furthermore, only one BCP (14.3%) was aware of a 'nervous' feeling when she participated with the negative scenario. She commented *'well, the numbers are coming in a second' (B2)*. The others said they were not aware of a specific negative or positive feeling (n=6; 85.7%).

In the PCP group, all participants agreed that it was a good idea to show the warnings (n=4; 100%). In this group one participant (25%) was sceptical about the terms 'good news' and 'bad news'. He commented *'good and bad news, this is in brackets but there is still some sort of value in these terms and I am not sure if you need to give them so much value' (P1).* Otherwise the PCPs did not have much feedback as the content was clear and logical. Two PCPs (50%) that were participating in the negative scenario mentioned an 'anxious' they felt while reading the warnings, as they were becoming afraid for the statistics that they were about to see.

4.2.1.3. General or personalised statistics. In the BCP group, the term personalised statistics' was considered an appropriate term by most participants (n=6; 85.7%). However, one BCP (14.3%) did not agree and thought it was an inappropriate term. She said *'it gives me the feeling that the statistics are specifically about me as a person, while they are actually* *about patients with the same disease characteristics. So, I am unsure if you need to use that term in that way' (B3)*. Furthermore, most of the BCPs preferred to see the long and detailed version (n=6; 85.7%), in order to be better informed about the difference and the terms in general (n=4; 66.7%), and to have a moment to realise if the information was really they wanted (n=2; 33.3%).

Within the PCP group, the term 'personalised statistics' was considered an inappropriate term by most participants (n=3; 75%). Two of the PCPs mentioned that the term was deceitful, and the other PCP thought it was hard to pronounce. Furthermore, two PCPs (50%) had a preference for the long and detailed version in which explanation was provided. The other two PCPs (50%) had a preference for the short and concise version with only the direct question for general or personalised statistics.

4.2.2. Part II - entering data.

4.2.2.1. Personal data. All BCPs indicated that they were not aware of a specific positive or negative feeling while entering the personal data (n=7; 100%). Furthermore, of the six BCPs who were asked about their preferences, five (83.3%) preferred to see the short and concise version from which the introductory text was omitted. Their reasons were that, *'it does not add much', (B4),* and, *'they are simple questions that do not require an explanation. Besides, I want those statistics, so I will provide this information anyway' (B6)*. Another BCP (16.7%) did not initially notice the introductory text, although she mentioned during the interview when reading the text that she preferred to see this introductory information *(B5)*. All BCPs said that it was easy to enter the personal data, navigation technically (n=7; 100%).

In the PCP group, one PCP (25%) mentioned that he was aware of a 'sad' feeling, as he realised that the man from the given scenario was far too young to be diagnosed with prostate cancer. Furthermore, of the two PCPs (50%) who were asked about their preferences, one (50%) preferred the long and detailed version with introductory text, while the other

(50%) preferred to see the short and concise version without introductory text, which he thought was unnecessary. Of the two PCPs (50%) who were asked to indicate the ease of entering personal data navigation technically, two participants (100%) indicated that it was easy.

4.2.2.2. Disease-related data. Within the BCP group, two participants (28.6%) were aware of a 'negative' feeling when entering the disease characteristics. For example, one realised in the negative scenario that the characteristics she entered were not very positive and this brought up a negative feeling. Six BCPs (85.7%) were asked about their preferences. Regarding their preference for the introductory text, four BCPs (66.7%) indicated that they preferred the short and concise version without this introduction, and two BCPs (33.3%) indicated that they preferred the long and detailed version with the introduction. Regarding the preference for automatically showing the extra explanation field or having the option to open this field, four BCPs (66.7%) preferred the long and detailed version in which this extra explanation was automatically shown and two BCPs (33.3%) preferred the short concise version with the option to open the extra explanation. Furthermore, out of the six participants (85.7%) who were asked about the characteristic 'stage', for four (66.7%) this was a well-known characteristic. However, two BCPs (33.3%) had heard of the characteristic before but they did not know what it meant. In their personal situation this characteristic was never mentioned. Participants also provided suggestions for adding more disease characteristics such as the location of the tumour *(B3),* the specific type of breast cancer *(B3)*, hormone sensitivity *(B3),* and type of treatment *(B5)*. Furthermore, of the three BCPs (42.9%) who were asked to indicate the ease of entering disease characteristics, three participants (100%) indicated that this was easy to do.

In the PCP group, three participants (75%) commented while thinking out loud something on how they felt, as they noticed that very negative data was included in the negative scenario. This might indicate worried feelings. One of them (33.3%) also mentioned when entering the characteristics from the better scenario, *'this man does not need to worry very much' (P3)*. This could be interpreted as a comforted feeling. Furthermore, of the two PCPs (50%) who were asked about their preferences, both (100%) preferred the short and concise version without the introductory text. However, with regard to their preference for automatically showing extra information about the questions (long and detailed version) or creating an option to open this extra information (short and concise version), only one (50%) also preferred the long and detailed version. Meanwhile, three PCPs (75%) were not familiar with the characteristic 'stage' at all, as in their personal situation this characteristic was never given. Two PCPs (50%) gave feedback about the margins provided in the answer options for the Gleason score and PSA value. For example, one commented, *'I think those margins, from -20 to +20, are far too big, that is really strange' (P4)*.

4.2.3. Part III – receiving results.

4.2.3.1. Summary of the data. Out of five BCPs (71.4%) who were asked for their preference in showing the summary, most chose the table in the short and concise version as this was much clearer in their opinion (n=4; 80%). For example, one commented, *'I find the table clearer. You have to read less and can see it at a glance. Also, you can easily see if you have filled in something in incorrectly' (B1)*.

In the PCP group, all participants also had a preference for the short and concise version in which the data and characteristics were displayed in a table (n=4; 100%). They agreed that this was much clearer, as you can see the data at a glance.

4.2.3.2. Incidence rates. In the short and concise version four patients (57.1%) from the BCP group clicked on the question mark to see more explanation about the term 'incidence'. Two others (28.6%) that did not click on the question mark noted that they knew what the term meant. Furthermore, five of the seven BCPs (71.4%) expressed a feeling while reading out loud. Three of them (60%) were shocked by seeing the general incidence rate. However, four of them (80%) were less shocked when seeing the personalised incidence rate in both scenarios. They mentioned things like, *'in 2016 there were 81 women with the diagnosis of stage one. 'So… well, that is not much'*, *(B4)*, and, *'70 women with an age of 46 well, I think that is not much. But what if it is you…' (B5)*. Meanwhile, one BCP (14.3%) again had some issues with the formulation. She suggested to add that the statistics are based on Dutch patients, and she did not like the use of the word 'cases' to describe patients *(B3)*.

Within the PCP group, three patients (75%) clicked on the question mark to see more explanation about the term 'incidence'. Furthermore, two PCPs (50%) expressed a feeling while reading out loud. One was shocked by the large general incidence rate. He said, *'oh, that is a lot of people, 11,000' (P3)*. However, they both were surprised by the personalised number being so low.

4.2.3.3. Survival rates. Overall, this category received a lot of attention during the evaluation. First of all, in the BCP group six patients (85.7%) expressed a negative or positive feeling while reading the general and personalised survival rates. Overall, the scenario had an impact that created feelings. Regarding the personalised rate in the unfavourable scenario, all six of the BCPs experienced an intense negative feeling. For example, one said *'so, oh dear, so, well, that is worrying' (B5)*. In the favourable scenario, three BCPs (42.9%) expressed while thinking out loud a positive feeling when seeing the personalised rate. Additionally, four BCPs (57.1%) also expressed a positive feeling when seeing the general rate. One said, *'yeah, with 88 percent, then you still have kind of a hooray feeling' (B7).* However, someone else commented that seeing the general number in contrast to the personalised number can be very frustrating when a patient has an unfavourable scenario *(B5)* (n=1;14.3%). Moreover, out of the three BCPs (42.9%) who were asked about their preference for seeing both the general and the personalised number, three BCPs (100%) preferred to see only the personalised number. Furthermore, when asking three BCPs (42.9%) about if they preferred to see the terms ‘general’ and ‘personalised’ by name and indicate them with bold (which was done in the short and concise version) or not, they all preferred the use of indicated terms (n=3; 100%). They agreed that this was much clearer. Additionally, three BCPs (42,9%) also mentioned in the long and detailed version that they were confused about what the general and what the personalised number was. Out of the five BCPs (71.4%) who were asked whether they missed any information when seeing the numbers, three (60%) suggested that more information could be shown about the specificity of the tumour, the reliability of the numbers, incidence and survival rates for ten years, and incidence and survival rates from people who have not been diagnosed at all. Finally, some more feedback was provided about the formulation of the text.

In the PCP group, two patients (50%) expressed positive feelings when seeing the general number and the personalised number in the favourable scenario. For example, they mentioned, *‘when seeing the 94 percent I got a comfortable feeling, like, I still have a while to go’, (P3)* and, *‘89 percent, well that gives me hope’ (P4)*. However, they also expressed a negative feeling when confronted with the personalised number from the unfavourable scenario. They said *‘47, shit… half of them are dead…’ (P3)*, and, *‘it is a fact, but it does not make me happy. Then you are one in two’ (P4)*. Furthermore, one PCP (25%) preferred to see both the general as the personalised numbers because that seemed like an added value to him. However, another PCP was strongly doubting in his preference, since in his eyes the general number was indeed informative, but it was still not concrete information for his situation (n=1; 25%). One PCP (25%), when asked whether he preferred to see the terms ‘general’ and ‘personalised’ by name and indicate them with bold (which was done in the short concise version) or not, he preferred to see the indicated terms from the short and concise version.

Additionally, one other PCP (25%) mentioned his confusion upon reading the survival rates in the long and detailed version regarding what the general and personalised numbers were.

4.2.3.4. Figures. Within the BCP group, three patients (42.9%) noted that it was not clear in either version that there was an option to switch between different types of figures. However, out of five BCPs (71.4%) who were asked about if having the control to switch between different type of figures was valuable or not, four patients (80%) agreed it was valuable, since not everyone has the same preferences regarding the type of figure. The other patient was not sure if it would be necessary to provide people with these different figures, because in her opinion interpreting the statistics is not very complex, so it is not necessary to provide different figures (n=1; 20%). Overall, the patients' preferences and opinions about the different types of figures are in great contrast to each other. Five BCPs (71.4%) were asked about their overall preference regarding the figures. No distinction was made by the researcher or the participants between the favourable and unfavourable scenarios regarding this preference. Two BCPs (40%) chose the icon arrays because they felt its impact *(B4 and B7)*. However, others said they felt its impact too much, or not at all, or that it was not clear at a glance. One BCP (20%) preferred to see the bar graph because that was the clearest to her *(B1)*, although another BCP said, *'the bar graph, that is a crazy one' (B5)*. One other BCP (20%) preferred to the pie chart because she felt its impact, and it was clear at the same time *(B6)*. The other BCP did not have a preference *(B5)* (n=1; 20%). None of the participants preferred the line graph, although some BCPs said it was a clear figure. Besides, one BCP (14.3%) said that it was not sufficiently clear which numbers were represented in the figures, specifically, if this were the general numbers or the personalised numbers *(B5)*.

In the PCP group, all patients mentioned that it was unclear in both versions that there was an option to switch between different types of figures (n=4; 100%). Two participants (50%) also mentioned that they did not see the added value of the option to switch between the figures *(P1 and P4)*. However, the other PCPs mentioned that they liked having this option to switch (n=2; 50%). For example, one said, *'I like the option to switch, because all patients have their own preference for a figure' (P3)*. Here the overall preferences and opinions also differed a lot. All of the PCPs mentioned something about their preference regarding the figures (n=4; 100%). No distinction was made by the researcher or the participants between the favourable and unfavourable scenarios regarding this preference. Two BCPs (50%) preferred the use of icon arrays, as they found it very clear *(P3 and P4)*. One of them (50%) also said that the line and bar graph were very confronting for him *(P3)*. However, one other PCP (25%) did not like the icon arrays because he needed to count the icons and could not easily see what the figure was trying to communicate *(P2)*. The preference of this PCP was actually not to show any figure but to show only the statistics, although he did say that the pie chart and bar graph were clear to him *(P2)*. The other PCP did not have a preference among the figures *(P1)* (n=1; 25%). Overall, also in this group nobody preferred to see the line graph.

4.2.3.5. Conditional survival rate. In the short and concise version, two BCPs (286%) mentioned while thinking out loud that they did not know what the term 'conditional survival' meant, so they clicked on the question mark to see a further explanation. One other BCP (14.3%) mentioned while thinking out loud that in both versions she did not understand how the survival rate was able to increase (B2). Furthermore, four BCPs (57.1%) mentioned that in their opinions providing the conditional survival rate, was very valuable and interesting. Additionally, six BCPs (85.7%) expressed a positive feeling upon seeing this rate. For example, one said *'that sounds positive, it makes me happy when I read that' (B6)*. However, one BCP (14.3%) also had again some feedback on the formulation of the sentences and words. For example, she commented that she did not like the word 'increase' (B3).

In the PCP group, two PCPs (50%) mentioned while thinking out loud that they did not understand the term ‘conditional survival’ and that they therefore clicked on the question mark to see further explanation. One other PCP (25%) mentioned while thinking out loud that in both versions he did not understand how the survival rate was to increase (P2). For the other participants, the explanation was very logic and clear overall. Of the two PCPs (50%) who were asked whether they thought it was valuable to show this information, they replied that they thought it was helpful and valuable.

4.2.3.6. Explanation on the statistics. Overall, the explanation on the statistics was very clear to all BCPs (n=7; 100%). Two BCPs (28,6%) mentioned that this explanation was very helpful and that it was a good addition to the results. However, one BCP (14.3%) mentioned that she missed some information from this part about the reliability of the statistics. Furthermore, two BCPs (28.6%) expressed a feeling of frustration when reading that the statistics were based on numbers up to 2017, as they wanted to see more recent numbers.

The PCP group also found the explanation on the statistics to be very clear overall (n=4; 100%). Out of two BCPs (50%) who were asked whether they thought this part was helpful, they both (100%) agreed that it was helpful and useful. However, one BCP (25%) was very frustrated by the fact that the statistics were based on numbers up to 2017 *(P4)*.

4.2.3.7. General preferences for results. Within the BCP group, all BCPs were asked if they preferred the short and concise version, in which all categories including the most important information were automatically shown, or the long and detailed version, in which only the titles of the categories were shown initially and the patients could click on them to reveal the corresponding information (n=7; 100%). Three patients (42,9%) preferred to see the short and concise version and three patients (42.9%) preferred to see the long and detailed version. One patient (14.3%) did not have a preference.

All of the PCPs also indicated their preference in this difference (n=4; 100%). Three patients (75%) preferred to see the short and concise version, while one patient (25%) preferred to see the long and detailed version.

Of the five BCPs (71.4%) who were asked about their preference regarding the titles of all categories in the results section, all five (100%) preferred to see the long and detailed version with simple sentences as titles instead of the official terms as titles, since this was easier to understand.

In the PCP group, three patients (75%) were asked about their preference for this difference. They all preferred to see the long and detailed version as this was easier (n=3; 100%). The other patient did not specifically indicate his preference specifically, but did mention that he did not understand all of the terms (n=1; 25%).

4.2.4. General remarks.

4.2.4.1. General feedback about the tool. Some patients also had some general feedback regarding the tool. Two BCPs (28.6%) mentioned that they wanted to see a confidence interval for the statistics. One BCP (14.3%) also indicated that she wanted to know more about the characteristics of the entire group. Meanwhile, two PCPs (50%) mentioned that they wanted to see even more concrete statistics, based on more characteristics than were asked.

4.2.4.2. Intention to use. The patients also indicated whether they would have used this tool if it was available at the time of their diagnoses. From the BCP group, four patients (57.1%) said they would have used the tool to obtain more specific information. The three remaining patients (42.9%) said that they would not have used the tool, because they simply did not want to know all of this information. However, one of these three (33.3%) indicated that after two years she would have changed this opinion, and probably would have used the tool.

In the PCP group, three patients (75%) also indicated that they would have used the tool at the time of their diagnoses. Only one patient (25%) said he would initially not have used the tool, but probably would have used it after a while.

4.2.4.3. General experience. In the BCP group the general experience was overall very positive (n=4; 57,1%). For example, one said *'yeah, I think this is a very good addition for kanker.nl' (B5,)* and another mentioned, *'yeah, it is easy and pleasant to use'*. However, one BCP (14.3%) noted that it was very shocking and emotional for her.

In the PCP group, out of the two patients (50%) who were asked about the general experience, they both (100%) had a positive experience. One said, *'yeah, this is very valuable' (P3)*.

5. Discussion

5.1. Principal findings and comparison with previous work

The aim of this study was to provide insights into what type of presentation format is most suitable for communicating personalised cancer statistics (i.e., incidence-, survival-, and conditional survival rates) to cancer patients (BCPS and PCPs). The participants (seven BCPs and four PCPs) evaluated a short and concise, and long and detailed presentation format, on its content, their feelings, their preferences, and navigation and layout.

Overall, it can be concluded that women (the BCP group) used more words to evaluate the different mock-up versions of the tool than men (the PCP group). This seems obvious since it is widely known that in daily speaking, women also use more words than men. However, men used more words in general within the interview sessions than women, but within the think-aloud sessions women in general used most words for the evaluation. Furthermore, most words were used by both groups to evaluate the long and detailed presentation in combination with the favourable scenario. It might be speculated that this version received most comments and feedback on its content. However, samples were too small to draw conclusions.

In the first part of the tool, ‘getting started’, three categories were evaluated. There were no contrasting opinions between both formats regarding the purpose and informativeness of the content in the introduction. Besides, the stated preference for the introduction was for the short and concise format. Therefore, it can be concluded that using the short and concise version for the introduction would probably be accepted by most of the patients. Since people are able to focus on particular prioritised aspects in material that they encounter to avoid information overload (Baddeley, 1992; Wilson & Wolf, 2009), when the patients approached the long and detailed version, they likely concluded that some of the information in this format was not priority information, and thus, preferred the short format. Furthermore, all patients appreciated the presentation of the warning statements, as this was valuable and necessary information. In addition, most patients preferred the long and detailed format with explanations and the choice of general or personalised statistics, because they believed this explanation was necessary to understand the terms correctly. It could be concluded that the explanation made the content more patient-friendly (Bolle et al., 2016; Wilson & Wolf, 2009), and therefore most of the patients preferred to see this. Overall, in all categories in the ‘getting started’ section, patients mentioned that some parts of the content were formulated too vaguely or were too difficult. This may be due to the technical terms used in the content, which made it content harder to understand and patient-unfriendly (Bolle et al., 2016; Wilson & Wolf, 2009). Therefore, the reformulation of some parts in the ‘getting started’ section should be considered.

In the second part of the tool, ‘entering data’, two categories were evaluated. Regarding the emotional state of the patients, entering personal data did not generally have a large impact. However, emotion became a stronger influence when disease-related data had to be entered. This was mostly because patients understood they were in a good or bad situation and consequently realised that they were about to face the results. Furthermore, since the introductory text was evaluated as unnecessary when entering personal data, it can be concluded that the short and concise version would be accepted by most of the patients. Again, this might be due to the fact that the introductory text in the long and detailed version was not prioritised as important (Baddeley, 1992; Wilson & Wolf, 2009). For entering disease-related data, the preferences for presentation format were not consistent. This could be explained by personal differences such as education level (i.e., some patients needed the extra explanation while others did not). The best option may be not to show the introduction text in the first place but to add an option to reveal this text. Furthermore, although it is probably necessary to automatically show the extra explanation about the content, an option could also be created to collapse this explanation. Options to expand text were also suggested by Bolle et al. (2016). Besides, important disease-related terms were not familiar for everyone. Instead of these technical terms, reformulation or a better explanation might be considered to make the content more patient-friendly (Bolle et al., 2016; Wilson & Wolf, 2009). Furthermore, some patients mentioned that they wanted to enter even more disease-related data than was possible. The cancer statistics will ultimately eventually be more truthful and complete when more disease-related data can be entered, and truthful and complete statistics are what many cancer patients want and need (Fletcher et al., 2017). Overall, when entering the ‘personal data’, the ease of entering data navigation technically was evaluated as simple. The navigation elements were identical in the second category, ‘disease-related data’. Although, not all of the patients mentioned the ease of entering data in the second category, it could be concluded that since this was evaluated as easy in the first category, this is also the case for the second category. An explanation for this positive evaluation could be that the navigation elements were all presented at the centre of the page, as suggested by Bolle et al. (2016). Another explanation, which is also in line with the study of Bolle et al. (2016), is that patients did not mind scrolling up and down, which was frequently necessary during navigation.

In the third part, ‘receiving results’, six categories were evaluated. Regarding the summary of the data, it can be concluded that the short and concise version is the best option to use, as a table is easier to scan important information from than a piece of text. This ease of prioritising information helps patients to avoid information overload (Baddeley, 1992; Wilson & Wolf, 2009). Overall, all the statistics – incidence, survival, and conditional survival – stirred up emotions in the patients, which was also expected because emotional experiences are a logical consequence of cancer diagnosis (Reyna et al., 2015; Shapiro et al., 2001). Moreover, the type of emotion strongly depends on the situation of the patient (favourable or unfavourable). Among the survival rates, the personalised survival rate was seen as valuable while the general survival rate was not appreciated by all of the patients. Some patients realised by seeing the personalised statistic, that the general statistic does not inform them about their personal situation, and therefore they did not like it. It can also be concluded that patients might be confused in the long and detailed version where the terms ‘personal survival rate’ and ‘general survival rate’ were missing. It is more difficult to prioritise important information in a large piece of text, and this may result in information overload (Baddeley, 1992; Wilson & Wolf, 2009), which in turn resulted in confusion. To avoid this issue, it would probably be better to use the short and concise version in which the terms are used and indicated in bold. Regarding the figures, it was not clear in both versions that there was an option to switch between the figures. This could be explained as the navigational elements were not centered on the page, and therefore patients did not notice them, which is in line with the study from Bolle et al. (2016). Therefore, this option needs to be made clearer with the help of better navigation, design, and content clues. Since, in the short and concise version less room is available for these clues, it is probably preferable to use the long and detailed format here. As, the preferences for type of figure were not in line for both groups, it can be concluded that there is no best figure to show. Therefore, the option to switch between type of figure may be valuable. In addition, showing the conditional survival rate was considered very valuable. With this extra information the cancer statistics were even more truthful and complete than without, which is exactly what the patients need (Fletcher et al., 2017). However, the explanation was not completely clear for all patients, which may be due to the technical terms that were used in the explanation, which made it patient-unfriendly (Baddeley, 1992; Wilson & Wolf, 2009). Thus, reformulation should be considered. Regarding the explanation of the statistics, it can also be concluded that this part is valuable, since patients mentioned that it was helpful and useful. Therefore, this contributed to a more patient-friendly text. Furthermore, in regard to how the information (categories and belonging information) in the results section was displayed, patient preferences were not in line. This may be due to personal differences. Therefore, an option could be add whereby patients can indicate beforehand how they want to view the results. However, regarding the preference for the category titles, it can be concluded that that the long and detailed version with simple sentences as category titles would be best to use, as titles without technical terms are more patient-friendly than titles with only technical terms (Baddeley, 1992; Wilson & Wolf, 2009).

The intention to use the tool also varies per patient, and therefore clear conclusions cannot be drawn. This may be explained as not all patients desire detailed information at all stages of their illness (Leydon et al., 2000). However, it could be expected that future patients using the tool already have the intention to view these personalised statistics, since they will think beforehand about whether they want to see this information. Finally, it can be concluded that using the tool was a positive experience for most patients, because the provided information contributed to a more truthful and complete picture of their personal situation, which was what they wanted (Fletcher et al., 2017).

5.2. Strengths and limitations

The goal in for the number of participants in this study, was set at 16 patients in total, with which eight BCPs and eight PCPs. However, due to the lack of applications from patients to participate in this study, in addition to time constraints, the total number of participants remained at 11, of which seven were BCPs, and four were PCPs. This resulted in unequal groups of patients, causing that the conditions in the sessions were not equal. More importantly, this meant that less data was returned from the PCP group, which may cause incomplete results. Nevertheless, the stimuli for both groups was very similar in most categories. For example, the three categories in the getting started part were identical for both groups, except for the selection of the disease (breast or prostate cancer). Therefore, the data collected about these categories is based on 11 patients. Overall, these 11 patients provided a lot of data, as they participated in both a think-aloud session and a semi-structured interview. Hence, the total quantity of data produced from this study is still significant.

Furthermore, regarding the think-aloud sessions, the participants were asked to empathise with a scenario. However, some participants still used or thought of their personal situations without noticing. In total four BCPs (57.1%) and four PCPs (100%) reverted to their personal situations at least once during the think-aloud sessions. This may have influenced the sessions. For example, the emotions that arose with their personal situation may have influenced their information processing (Wilson & Wolf, 2009), which in turn may have influenced their opinions. Another example is that the results of the patient in the scenario were compared to the patients’ personal situations. Subsequently, the patients only thought of what these results meant for themselves and not what they meant for the patient in the scenario. Overall, this may have resulted in unequal performances of the task in the think-aloud sessions. However, thinking of personal situations may also have been positive, since the reactions of patients then came closer to what the patients themselves really thought of the tool, and this data may also be valuable.

Since the participants needed to perform the task in both presentation formats, in some cases they recognized the content from the first session. For example, some participants had read the explanation of incidence rates in the long and detailed format during the first session. As a result, they knew the meaning of the incidence rate during the second session without reading the explanation. Consequently, the participants did not mention the difficulty of the term in the second session while thinking aloud. This could be seen as disproportionate treatment of the sessions. Since the division of the conditions is also not completely fair, this may have created a reduction of the quality of the data. However, the order in which the different versions of the format were displayed was randomised. Therefore, recall of information in the second sessions may have taken place in all sessions and all versions, in which case this possible reduction of the quality of the data is proportional for both formats.

Furthermore, the stimuli used in the sessions were mock-up versions of the tool. In some sessions this produced minor misunderstandings or navigation problems. For example, two BCPs (28.6%) commented that they did not understand what ‘the above-mentioned characteristics’ were, since they did not see any characteristics. This resulted in confusion and had a slightly negative influence on the rest of the task in some of the sessions. Therefore, the researchers decided to provide some instructions in the case where these confusions produced problems for the tasks. Consequently, the think-aloud method was not been fully accomplished. However, the misunderstandings created no major problems and providing the patients with instructions enabled the continuation of the task. The provision of instructions is not allowed according to the framework of Ericsson and Simon (1980); however, in the framework of Boren and Ramey (2000), it is permitted to use speech communication when dealing with technical problems. Subsequently, it could be concluded that the framework of Boren and Ramey eventually was applied more than the framework of Ericsson and Simon.

Another important limitation of this study concerns the semi-structured interviews. This method had its advantages since the researcher could go into specific directions of the research question while also creating the possibility for the participants to offer new meanings and insights for the study (Galletta, 2013). However, looking back it can be concluded that many important questions were not posed to all of the participants in both of the groups. This resulted in incomplete data, and comparisons and conclusions could therefore not always be made for the entire group. For example, in the ‘personal data’ category, only half of the PCP group were asked if they preferred to see the introductory text. In other words, the preference of the short and concise format or the long and detailed format was only determined for half of this group. However, in almost all cases questions were asked to at least a few participants and sometimes to nearly all of them. This data was enough to be able to draw conclusions and to create a representation of what the entire group would have said.

Lastly, transcribing and coding all the data from both the think-aloud and the interview sessions was done by one researcher. Errors could unknowingly be made, and the researcher could have missed parts by accident during transcribing and coding. Moreover, possible inconsistencies in the codes were not checked. This may have resulted in unreliable data. However, due to time constraints it was not possible to perform the transcribing and coding processes more than once and by other researchers. Nevertheless, since the transcribing and coding processes were performed by one researcher, everything was assessed in the same way.

5.3. Directions for future research

This study provides evaluations and preferences for the communication of personalised cancer statistics, gathered from BCPs and PCPs. Future studies should also investigate these evaluations and preferences with other cancer patients, as they might have other evaluations and preferences. For example, patients with pancreatic cancer generally have poorer prospects than those with breast and prostate cancer. This may have an impact on their specific preferences for communication of their personal statistics.

Additionally, future studies should investigate what insights the relatives of cancer patients can provide, since they may also use this tool, and may view it differently to patients. For example, they might have less knowledge than the cancer patients about the disease, and therefore it may more difficult to enter the personal and disease-related data. However, they also have to cope with the cancer of their loved ones, so it is therefore necessary to evaluate if the relatives of cancer patients appreciate the same types of communication from this tool as the cancer patients themselves.

Furthermore, since the semi-structured interviews did not fully capture all of the important evaluations and preferences from all of the cancer patients, future research could also consider adding another research method. For example, instead of asking all patients about their preferences for every difference within the presentation formats with the use of a semi- structured interview, a questionnaire could be used. The advantage of asking about their preferences with a questionnaire is that no important questions will be skipped. In addition, a semi-structured interview could be used to ask further questions about their preferences and other evaluations.

Another direction for future research could be to evaluate how a presentation format with a more story-like way of presenting (i.e., a narrative), would be evaluated by the patients. Since telling or showing stories of patients seems to be more authentic, appealing, and credible than only documentation of facts (Aaker & Aaker, 2016), this might be an even better method to use when communicating personalised cancer statistics.

Finally, future research could also investigate if the emotions that may arise when using this tool, have an effect on the recall of the information. In this study it can only be concluded that emotions arise for most of the patients when provided with the information in the tool. However, this study can only speculate on whether these emotions have an effect on recall of the information. If this does occur, the communication might need to be carried out.

5.4. Implications

No findings from the existing literature explicitly focus on the field of communicating personalised cancer statistics. Therefore, the aim of this study was to be exploratory. In that respect, this study contributes to the development of knowledge for the communication of personalised health information, specifically cancer statistics. The insights from this study may be of great importance for other research in the field of communicating personalised statistics, as well as for the further development and launching of the tool at kanker.nl. The qualitative data gathered in this study will eventually be valuable for cancer patients as they can really benefit from the provision of personalised cancer statistics, provided that these are properly communicated to them.

5.5. Conclusions

This study shows how breast and prostate cancer patients evaluate a short and concise, and a long and detailed presentation format for communicating personalised cancer statistics. Overall, the evaluations of both patient groups are divergent. There is no clear preference for either format. Thus, when communicating personalised cancer statistics, some parts of the information need to be communicated in a short and concise manner, whereas other parts should be communicated in a long and detailed manner. These preferences deviate per person and the preferences of patients mostly differed from those of the other patients, therefore conclusions are not clear. However, structured information is preferred in all cases. Furthermore, being provided with personalised cancer statistics can be a positive or negative emotional experience, regardless of the used presentation format. It is important that the content in the presentation format is patient-friendly. Therefore, the use of technical terms needs to be avoided, but when this is not possible a proper explanation must be provided. These results serve as a base for further developments in communicating personalised cancer statistics. However, conducting more research in this area is strongly recommended in order, to ultimately improve the communication of personalised health information, and specifically cancer statistics.

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Appendices

Appendix A

Invitation letter

Uitnodiging deelname onderzoek naar informatie over overlevingscijfers bij kanker

Beste meneer/mevrouw,

Hierbij willen we u uitnodigen om deel te nemen aan een onderzoek van Tilburg University en het Integraal Kankercentrum Nederland (IKNL). Het onderzoek gaat over hoe patiënten en naasten informatie willen ontvangen over o.a. gepersonaliseerde overlevingscijfers bij kanker.

Wat houdt dit onderzoek in?

Het doel van dit onderzoek is het verkrijgen van inzichten over hoe gepersonaliseerde getallen over kanker, zoals overlevingscijfers, het beste aangeboden kunnen worden richting patiënten. Hiervoor zal een eerste versie van een website worden doorlopen waarbij de presentatie van deze getallen centraal staat. Tijdens het doorlopen van deze webpagina’s vragen wij u om hardop uit te spreken waarom u kiest om iets wel/niet in te vullen en waarom u wel/niet klikt op bepaalde knoppen.

Wat houdt meedoen aan dit onderzoek in?

Het onderzoek bestaat uit vier onderdelen en zal ongeveer 60 minuten in beslag nemen.

1. In het eerste onderdeel krijgt u uitleg over het onderzoek en stelt de onderzoeker een aantal vragen over uw achtergrond.
2. Daarna krijgt u een situatie van een patiënt uitgelegd, die anders is dan uw persoonlijke situatie. Vanuit die situatie vraagt de onderzoeker om de opdrachten uit te voeren. Tijdens het uitvoeren van de opdracht, vraagt de onderzoeker u om hardop te zeggen wat u denkt.
3. Daarna volgt een korte onderbreking/pauze, waarin de eerste opdracht kort besproken zal worden. Dan vragen wij u om de opdracht nogmaals uit te voeren. U zult dus in totaal twee keer dezelfde opdracht doorlopen.
4. Zodra beide opdrachten voldaan zijn volgt nog een kort gesprek, waarin de onderzoekers vragen zullen stellen over uw ervaringen bij het uitvoeren van de opdrachten.

Wie kunnen meedoen aan dit onderzoek?

U kunt meedoen aan dit onderzoek als u:

- In het verleden de diagnose **prostaat**- of **borstkanker** heeft gehad;
- De Nederlandse taal beheerst;
- Overweg kunt met een computer;

Kan ik mij op elk moment terugtrekken?

Deelname aan dit onderzoek is geheel vrijwillig. Als u deelneemt, vragen wij u om schriftelijk toestemming te geven om uw gegevens te gebruiken voor dit onderzoek. U heeft altijd het recht om op elk moment te stoppen zonder een reden op te geven.

Hoe kan ik meedoen aan dit onderzoek?

Als u interesse heeft om deel te nemen aan dit onderzoek, vragen wij u om uw naam, e-mailadres en telefoonnummer door te geven. Wij nemen dan contact met u op om een afspraak te maken over wanneer en waar het onderzoek kan plaatsvinden, bij u thuis of op een van de IKNL-locaties (Eindhoven, Utrecht, Amsterdam, Rotterdam, Nijmegen).

Alvast heel erg bedankt voor uw medewerking.

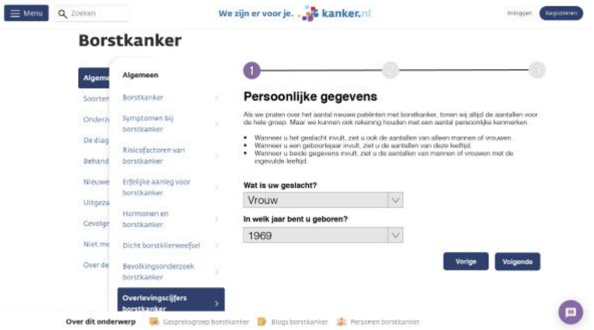
Met vriendelijke groet,

Ruben Vromans - Onderzoeker Tilburg University

Appendix B

A few example screens of the 6 other mock-up versions

Breast cancer version of the long and detailed format in the unfavourable scenario, versus, breast cancer version of the short and concise format in the favourable scenario



Persoonlijke gegevens

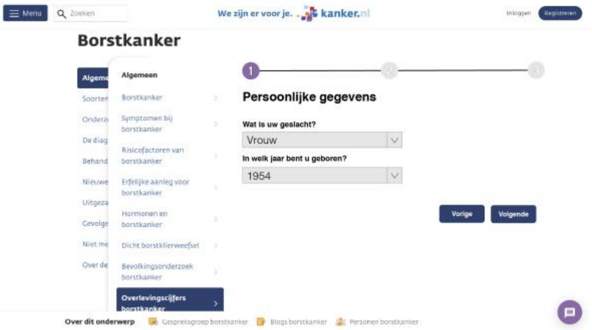
Als we praten over het aantal nieuwe patiënten met borstkanker, tonen wij altijd de aantallen voor de hele groep. Maar we kunnen ook rekening houden met een aantal persoonlijke kenmerken.

- Wanneer u het geslacht invult, ziet u ook de aantallen van alleen mannen of vrouwen.
- Wanneer u een geboortejaar invult, ziet u de aantallen van deze leeftijd.
- Wanneer u beide gegevens invult, ziet u de aantallen van mannen of vrouwen met de ingevulde leeftijd.

Wat is uw geslacht? Vrouw

In welk jaar bent u geboren? 1969

Personal data: breast, long, unfavourable



Persoonlijke gegevens

Wat is uw geslacht? Vrouw

In welk jaar bent u geboren? 1954

Personal data: breast, short, favourable

Gegevens over uw ziekte bij diagnose

We kunnen de cijfers nog meer op maat presenteren, wanneer u ook één of meerdere ziektekenmerken kunt invullen. Dit zijn gegevens over uw ziekte **bij diagnose**, zoals het stadium van de ziekte, en in welk jaar u de diagnose kreeg. Als u deze gegevens invult, kunnen wij overlevingscijfers tonen op basis van patiënten met ongeveer dezelfde ziektekenmerken bij diagnose. Ook nu is het belangrijk om na te denken of u wel cijfers wilt ontvangen op basis van deze gegevens. Als u bij alle kenmerken 'weet ik niet' invult, krijgt u de algemene cijfers te zien.

Wat was het stadium van de ziekte bij diagnose? Weet ik niet

Waren er uitzaaiingen gevonden bij diagnose? Ja, elders in het lichaam

Disease data: breast, long, unfavourable

Gegevens over uw ziekte bij diagnose

In welk jaar kreeg u de diagnose? 2016

Wat was het stadium van de ziekte bij diagnose? Stadium I

Disease data: breast, short, favourable

Resultaten

Op deze pagina ziet u cijfers over borstkanker. U heeft aangegeven om gepersonaliseerde cijfers te ontvangen, zodat deze uw situatie meer benaderen.

De cijfers die wij tonen, zullen daarom gebaseerd zijn op **vrouwen** die op **50-jarige leeftijd** de diagnose **uitgezaaide** borstkanker kregen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: breast, long, unfavourable

Resultaten

Op deze pagina ziet u cijfers over borstkanker. De cijfers die wij tonen, zijn gebaseerd op patiënten met de volgende kenmerken bij diagnose:

Geslacht: **Vrouw**	Diagnosejaar: **2016**
Geboortejaar: **1954**	Stadium: **Stadium I**

In **2016** kregen in totaal 14 752 vrouwen de diagnose borstkanker. In 2016 kregen 81 vrouwen de diagnose borstkanker stadium I op 65-jarige leeftijd.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: breast, short, favourable

Resultaten

Hoeveel vrouwen overleven borstkanker?

Met **overleving** bedoelen we hoeveel mensen met een bepaalde vorm van kanker na een bepaalde periode nog in leven zijn. In dit geval laten we zien hoeveel vrouwen met de diagnose borstkanker 5 jaar na diagnose nog in leven zijn.

Om betrouwbare getallen te geven, moet er gerekend worden met grote aantallen patiënten die in het verleden borstkanker hebben gehad. De cijfers die wij hier tonen zullen gebaseerd zijn op patiënten met de bovengenoemde kenmerken die tussen 2012 en 2017 de diagnose borstkanker kregen.

We laten eerst de kans op overleving zien van alle patiënten met borstkanker. 5 jaar na diagnose was ongeveer **88 procent** van de borstkanker patiënten nog in leven (88 van de 100 vrouwen).

We kunnen ook de kans op overleving laten zien van borstkanker patiënten die bij diagnose de bovengenoemde kenmerken hadden. 5 jaar na diagnose was ongeveer **38 procent** van deze patiënten nog in leven (38 van de 100 vrouwen).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, survival: Breast, long, unfavourable.

Resultaten

Algemene cijfer: 5 jaar na diagnose was ongeveer **88 procent** van de borstkanker patiënten nog in leven (88 van de 100 vrouwen).

Gepersonaliseerde cijfer: 5 jaar na diagnose was ongeveer **89 procent** van de patiënten met bovengenoemde kenmerken nog in leven (89 van de 100 vrouwen).

Het is belangrijk om te weten dat uw vooruitzichten nog steeds beter of slechter kunnen zijn dan de vooruitzichten voor deze specifieke groep. Bespreek uw vooruitzichten met uw arts.

5 jaar na diagnose

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, survival: Breast, short, favourable

Resultaten

De figuur hiernaast toont de **5-jaarsoverleving** van borstkanker patiënten met bovengenoemde kenmerken. U kunt het type figuur aanpassen naar uw wensen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 2: Breast, long, unfavourable

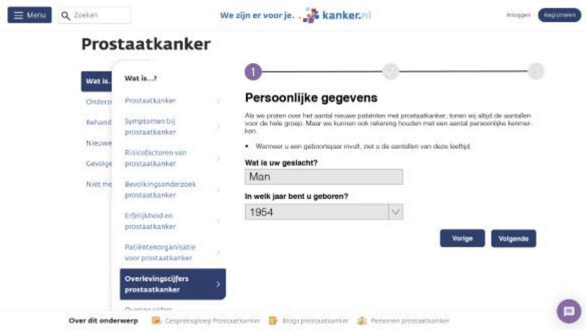
Resultaten

Van de patiënten met bovengenoemde kenmerken die 3 jaar na diagnose nog leefden, was de kans dat zij 5 jaar na diagnose nog in leven waren **gestegen van 89 procent naar 90 procent**

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 2: Breast, short, favourable

Prostate cancer version of the long and detailed format in the favourable scenario, versus, prostate cancer version of the short and concise format in unfavourable scenario



Persoonlijke gegevens

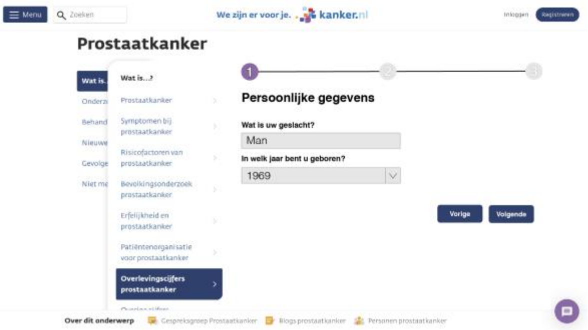
Als we praten over het aantal nieuwe patiënten met prostaatkanker, tonen wij altijd de aantallen voor de hele groep. Maar we kunnen ook rekening houden met een aantal persoonlijke kenmerken.

- Wanneer u een geboortejaar invult, ziet u de aantallen van deze leeftijd.

Wat is uw geslacht? Man

In welk jaar bent u geboren? 1954

Personal data: prostate, long, favourable



Persoonlijke gegevens

Wat is uw geslacht? Man

In welk jaar bent u geboren? 1969

Personal data: prostate, short, unfavourable

Gegevens over uw ziekte bij diagnose

We kunnen de cijfers nog meer op maat presenteren, wanneer u ook één of meerdere ziektekenmerken kunt invullen. Dit zijn gegevens over uw ziekte **bij diagnose**, zoals het stadium van de ziekte, en in welk jaar u de diagnose kreeg. Als u deze gegevens invult, kunnen wij overlevingscijfers tonen op basis van patiënten met ongeveer dezelfde ziektekenmerken bij diagnose. Ook nu is het belangrijk om na te denken of u wel cijfers wilt ontvangen op basis van deze gegevens. Als u bij alle kenmerken 'weet ik niet' invult, krijgt u de algemene cijfers te zien.

In welk jaar kreeg u de diagnose? 2016

Wat was uw PSA-waarde bij diagnose? Lager dan 10

Wat was uw Gleason-score bij diagnose?

Disease data: prostate, long, favourable

Gegevens over uw ziekte bij diagnose

2015

Wat was uw PSA-waarde bij diagnose? Hoger dan 20

Wat was uw Gleason-score bij diagnose? Hoger dan 7

Wat was het stadium van de ziekte bij diagnose? Stadium IV

Disease data: prostate, short, unfavourable

Resultaten

Op deze pagina ziet u cijfers over prostaatkanker. U heeft aangegeven om gepersonaliseerde cijfers te ontvangen, zodat deze uw situatie meer benaderen.

De cijfers die wij tonen, zullen daarom gebaseerd zijn op mannen die op **65-jarige leeftijd** de diagnose prostaatkanker **stadium I** kregen (PSA-waarde kleiner dan 10, en Gleason-score lager dan 7).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: prostate, long, favourable

Resultaten

Op deze pagina ziet u cijfers over prostaatkanker. De cijfers die wij tonen, zijn gebaseerd op patiënten met de volgende kenmerken bij diagnose.

Geslacht: **Man**
Diagnosejaar: **2015**
Gleason-score: **Hoger dan 7**
Geboortejaar: **1969**
PSA-waarde: **Hoger dan 20**
Stadium: **Stadium IV**

In **2015** kregen in totaal 10.629 mannen de diagnose prostaatkanker. Als we rekening houden met de bovengenoemde kenmerken, kregen in 2015 70 mannen de diagnose prostaatkanker stadium 4 (PSA-waarde hoger dan 20, en Gleason-score hoger dan 7) op 50-jarige leeftijd.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: prostate, short, unfavourable

Resultaten

Met **overleving** bedoelen we hoeveel mensen met een bepaalde vorm van kanker na een bepaalde periode nog in leven zijn. In dit geval laten we zien hoeveel mannen met de diagnose prostaatkanker 5 jaar na diagnose nog in leven zijn.

Om betrouwbare getallen te geven, moet er gerekend worden met grote aantallen patiënten die in het verleden prostaatkanker hebben gehad. De cijfers die wij hier tonen zullen gebaseerd zijn op patiënten met de bovengenoemde kenmerken die tussen 2012 en 2017 de diagnose prostaatkanker kregen.

We laten eerst de kans op overleving zien van alle patiënten met prostaatkanker. 5 jaar na diagnose was ongeveer **89 procent** van de prostaatkanker patiënten nog in leven (89 van de 100 mannen).

We kunnen ook de kans op overleving laten zien van prostaatkanker patiënten die bij diagnose de bovengenoemde kenmerken hadden. 5 jaar na diagnose was ongeveer **94 procent** van deze patiënten nog in leven (94 van de 100 mannen).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, survival: prostate, long, favourable.

Resultaten

Algemene cijfer: 5 jaar na diagnose was ongeveer **89 procent** van de prostaatkanker patiënten nog in leven (89 van de 100 mannen).

Gepersonaliseerd cijfer: 5 jaar na diagnose was ongeveer **47 procent** van de patiënten met bovengenoemde kenmerken nog in leven (47 van de 100 mannen).

Het is belangrijk om te weten dat uw vooruitzichten nog steeds beter of slechter kunnen zijn dan de vooruitzichten voor deze specifieke groep. Bespreek uw vooruitzichten met uw arts.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

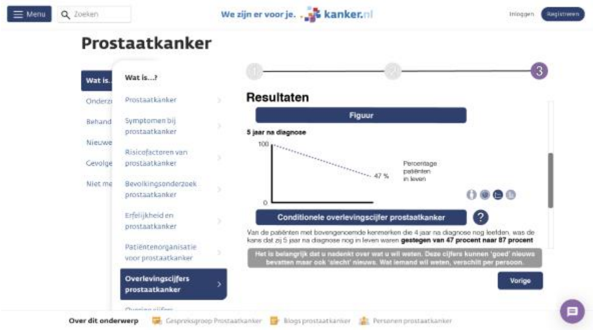
Results, survival: prostate, short, unfavourable

Resultaten

De figuur hiernaast toont de **5-jaarsoverleving** van prostaatkanker patiënten met bovengenoemde kenmerken. U kunt het type figuur aanpassen naar uw wensen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 3: prostate, long, favourable



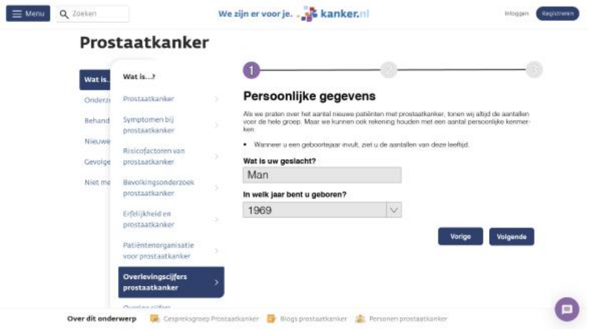
Resultaten

Van de patiënten met bovengenoemde kenmerken die 4 jaar na diagnose nog leefden, was de kans dat zij 5 jaar na diagnose nog in leven waren **gestegen van 47 procent naar 87 procent**

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 3: prostate, short, unfavourable

Prostate cancer version of the long and detailed format in the unfavourable scenario, versus, prostate cancer version of the short and concise format in favourable scenario



Persoonlijke gegevens

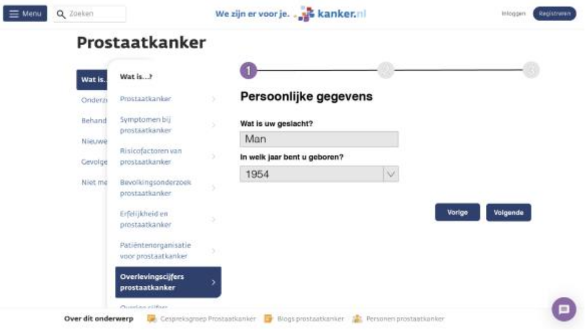
Als we praten over het aantal nieuwe patiënten met prostaatkanker, tonen wij altijd de aantallen voor de hele groep. Maar we kunnen ook rekening houden met een aantal persoonlijke kenmerken.

- Wanneer u een geboortejaar invult, ziet u de aantallen van deze leeftijd.

Wat is uw geslacht? Man

In welk jaar bent u geboren? 1969

Personal data: prostate, long, unfavourable



Persoonlijke gegevens

Wat is uw geslacht? Man

In welk jaar bent u geboren? 1954

Personal data: prostate, short, favourable

Gegevens over uw ziekte bij diagnose

We kunnen de cijfers nog meer op maat presenteren, wanneer u ook één of meerdere ziektekenmerken kunt invullen. Dit zijn gegevens over uw ziekte **bij diagnose**, zoals het stadium van de ziekte, en in welk jaar u de diagnose kreeg. Als u deze gegevens invult, kunnen wij overlevingscijfers tonen op basis van patiënten met ongeveer dezelfde ziektekenmerken bij diagnose. Ook nu is het belangrijk om na te denken of u wel cijfers wilt ontvangen op basis van deze gegevens. Als u bij alle kenmerken 'weet ik niet' invult, krijgt u de algemene cijfers te zien.

In welk jaar kreeg u de diagnose? 2015

Wat was uw PSA-waarde bij diagnose? Hoger dan 20

Wat was uw Gleason-score bij diagnose?

Disease data: prostate, long, unfavourable

Gegevens over uw ziekte bij diagnose

2016

Wat was uw PSA-waarde bij diagnose? Lager dan 10

Wat was uw Gleason-score bij diagnose? Lager dan 7

Wat was het stadium van de ziekte bij diagnose? Stadium I

Disease data: prostate, short, favourable

Resultaten

Op deze pagina ziet u cijfers over prostaatkanker. U heeft aangegeven om gepersonaliseerde cijfers te ontvangen, zodat deze uw situatie meer benaderen.

De cijfers die wij tonen, zullen daarom gebaseerd zijn op mannen die op **50-jarige leeftijd** de diagnose **prostaatkanker stadium 4** kregen (PSA-waarde hoger dan 20, en Gleason-score hoger dan 7).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: prostate, long, unfavourable

Resultaten

Op deze pagina ziet u cijfers over prostaatkanker. De cijfers die wij tonen, zijn gebaseerd op patiënten met de volgende kenmerken bij diagnose.

Geslacht: **Man**	Diagnosejaar: **2016**	Gleason-score: **Lager dan 7**
Geboortejaar: **1954**	PSA-waarde: **Lager dan 10**	Stadium: **Stadium I**

In 2016 kregen in totaal 11 114 mannen de diagnose prostaatkanker. In 2016 kregen 81 mannen de diagnose prostaatkanker stadium I (PSA-waarde kleiner dan 10, en Gleason-score lager dan 7) op 65-jarige leeftijd.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, summary: prostate, short, favourable

Resultaten

Met **overleving** bedoelen we hoeveel mensen met een bepaalde vorm van kanker na een bepaalde periode nog in leven zijn. In dit geval laten we zien hoeveel mannen met de diagnose prostaatkanker 5 jaar na diagnose nog in leven zijn.

Om betrouwbare getallen te geven, moet er gerekend worden met grote aantallen patiënten die in het verleden prostaatkanker hebben gehad. De cijfers die wij hier tonen zullen gebaseerd zijn op patiënten met de bovengenoemde kenmerken die tussen 2012 en 2017 de diagnose prostaatkanker kregen.

We laten eerst de kans op overleving zien van alle patiënten met prostaatkanker. 5 jaar na diagnose was ongeveer **89 procent** van de prostaatkanker patiënten nog in leven (89 van de 100 mannen).

We kunnen ook de kans op overleving laten zien van prostaatkanker patiënten die bij diagnose de bovengenoemde kenmerken hadden. 5 jaar na diagnose was ongeveer **47 procent** van deze patiënten nog in leven (47 van de 100 mannen).

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, survival: prostate, long, unfavourable.

Resultaten

Algemene cijfer: 5 jaar na diagnose was ongeveer **89 procent** van de prostaatkanker patiënten nog in leven (89 van de 100 mannen).

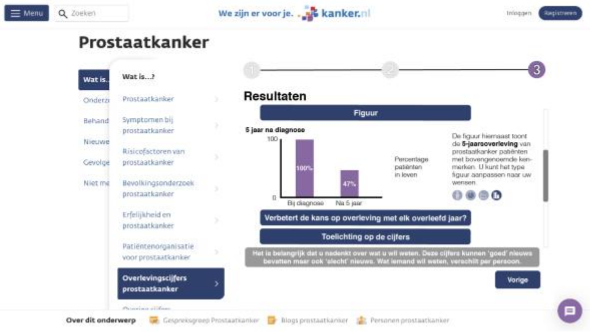
Gepersonaliseerd cijfer: 5 jaar na diagnose was ongeveer **94 procent** van de patiënten met bovengenoemde kenmerken nog in leven (94 van de 100 mannen).

Het is belangrijk om te weten dat uw vooruitzichten nog steeds beter of slechter kunnen zijn dan de vooruitzichten voor deze specifieke groep. Bespreek uw vooruitzichten met uw arts.

5 jaar na diagnose

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

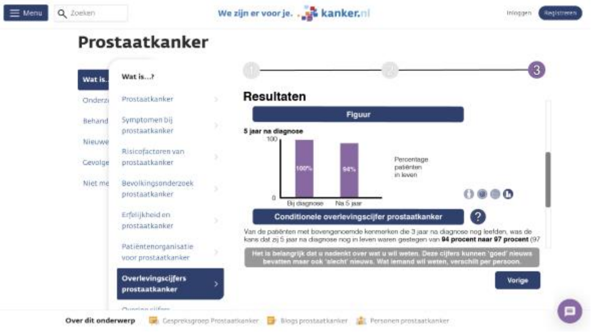
Results, survival: prostate, short, favourable



De figuur hiernaast toont de **5-jaarsoverleving** van prostaatkanker patiënten met bovengenoemde kenmerken. U kunt het type figuur aanpassen naar uw wensen.

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 4: prostate, long, unfavourable



Van de patiënten met bovengenoemde kenmerken die 3 jaar na diagnose nog leefden, was de kans dat zij 5 jaar na diagnose nog in leven waren gestegen van **94 procent naar 97 procent** (97

Het is belangrijk dat u nadenkt over wat u wil weten. Deze cijfers kunnen 'goed' nieuws bevatten maar ook 'slecht' nieuws. Wat iemand wil weten, verschilt per persoon.

Results, figure 4: prostate, short, favourable

Appendix C

The four scenarios

Scenario of a prostate cancer patient (patient X) with a favorable situation

Wij vragen u om de volgende situatie zo goed mogelijk voor te stellen.

Patiënt X (geboren in 1954) kreeg in maart 2016 de diagnose prostaatkanker, stadium I.

Bij diagnose maakte de uroloog via een bloedtest bekend dat meneer A een PSA-waarde had van 6 ng/ml.

Om de agressiviteit van de tumor te bepalen, bekeek de patholoog het weefsel onder de microscoop. Hij rapporteerde uiteindelijk een Gleason-score van 6.

Patiënt X heeft de ziekte al een aantal jaren overleefd. Toch is hij benieuwd hoeveel mannen "zoals hij" met prostaatkanker vijf jaar na diagnose nog in leven zijn.

Hij bezoekt daarom de website www.kanker.nl en probeert erachter te komen wat de overlevingskansen zijn voor mannen met prostaatkanker, stadium I (die bij diagnose dezelfde persoons-en ziektekenmerken hadden als hij).

Scenario of a prostate cancer patient with an unfavorable situation

Wij vragen u om de volgende situatie zo goed mogelijk voor te stellen.

Patiënt Y (geboren in 1969) kreeg in maart 2015 de diagnose prostaatkanker, stadium IV.

Bij diagnose maakte de uroloog via een bloedtest bekend dat meneer A een PSA-waarde had van 60 ng/ml.

Om de agressiviteit van de tumor te bepalen, bekeek de patholoog het weefsel onder de microscoop. Hij rapporteerde uiteindelijk een Gleason-score van 9.

Patiënt Y heeft de ziekte al een aantal jaren overleefd. Toch is hij benieuwd hoeveel mannen "zoals hij" met prostaatkanker vijf jaar na diagnose nog in leven zijn.

Hij bezoekt daarom de website www.kanker.nl en probeert erachter te komen wat de overlevingskansen zijn voor mannen met prostaatkanker, stadium IV (die bij diagnose dezelfde persoons-en ziektekenmerken hadden als hij).

Scenario of a breast cancer patient with a favorable situation

Wij vragen u om de volgende situatie zo goed mogelijk voor te stellen.

Patiënt X (geboren in 1954) kreeg in maart 2016 de diagnose borstkanker, stadium I.

Bij diagnose maakte de arts bekend dat de tumor ongeveer 1 centimeter was. Er waren verder geen uitzaaiingen naar de lymfeklieren in de oksel gevonden.

Patiënt X heeft de ziekte al een aantal jaren overleefd. Toch is zij benieuwd hoeveel vrouwen "zoals zij" met borstkanker vijf jaar na diagnose nog in leven zijn.

Zij bezoekt daarom de website www.kanker.nl en probeert erachter te komen wat de overlevingskansen zijn voor vrouwen met borstkanker, stadium I (die bij diagnose dezelfde persoons-en ziektekenmerken hadden als zij).

Scenario of a breast cancer patient with an unfavorable situation

Wij vragen u om de volgende situatie zo goed mogelijk voor te stellen.

Patiënt Y (geboren in 1969) kreeg in maart 2015 de diagnose borstkanker.

Bij diagnose maakte de arts bekend dat de tumor was uitgezaaid naar andere plekken in het lichaam.

Patiënt Y heeft de ziekte al een aantal jaren overleefd. Toch is zij benieuwd hoeveel vrouwen "zoals zij" met borstkanker vijf jaar na diagnose nog in leven zijn.

Zij bezoekt daarom de website www.kanker.nl en probeert erachter te komen wat de overlevingskansen zijn voor vrouwen met borstkanker (die bij diagnose dezelfde persoons-en ziektekenmerken hadden als zij).

Appendix D

Task description

Opdrachtomschrijving

U heeft zojuist een scenario ontvangen. Bekijk dit scenario goed en probeer de komende opdracht uit te voeren vanuit het perspectief van de patiënt uit dit scenario. U wordt gevraagd om persoonlijke gegevens en een aantal ziekte kenmerken in te vullen. Gebruik hiervoor de gegevens en ziekte kenmerken die omschreven zijn in het scenario, en dus **niet** uw eigen gegevens en ziekte kenmerken. Daarnaast dient u **alle** gegevens en ziekte kenmerken te gebruiken die beschreven zijn. U mag dus geen vragen overslaan of gegevens weglaten.

Uiteindelijk is het doel dat u **gepersonaliseerde incidentie- en overlevingscijfers** dient te vinden voor de patiënt in het scenario. Deze kunt u vinden nadat u alle gegevens en kenmerken hebt ingevuld. Hieronder staan nog een aantal punten waar u rekening mee dient te houden gedurende de opdracht:

- De tool die u gaat gebruiken is een prototype van een website en daardoor zal niet alles volledig werken zoals u gewend bent, probeer hier doorheen te kijken.
- Lees **alle** informatie die verschijnt goed door, en probeer geen delen over te slaan.
- Soms dient u te scrollen naar onderen om verder te kunnen, dit doet u door ergens onderin de scrol balk te klikken.
- U dient alle informatie in de juiste volgorde, van boven naar beneden, in te vullen.
- Niet alle knoppen die je ziet zijn klik baar. Alleen de knoppen die u ook daadwerkelijk nodig zou kunnen hebben om de opdracht uit te voeren kunt u dus gebruiken.
- Gedurende deze opdracht dient u alles wat u denkt en doet hard op uit te spreken.
- De onderzoekers zullen geen vragen beantwoorden, mits dit echt niet anders kan.

Zodra u denkt dat u klaar bent met de opdracht en niet meer verder kunt, kunt u dit aangeven.

Appendix E

Introduction as told by the researcher

Introductie uitleg

Allereerst, wil ik u vast heel erg bedanken namens mijzelf, Tilburg University en IKNL dat u de tijd heeft genomen om deel te nemen aan dit onderzoek. De resultaten zullen ten alle tijde anoniem worden verwerkt.

In dit onderzoek zal u twee verschillende prototypen van een tool doorlopen die in ontwikkeling is voor kanker.nl. Kanker.nl is het centrale online platform in Nederland met informatie over kanker. Op kanker.nl is betrouwbare informatie te vinden: over kanker, de gevolgen van de ziekte en andere dingen waar mensen met kanker mee te maken kunnen krijgen. Wat u momenteel vooral op kanker.nl kan vinden, zijn algemene cijfers over kanker. Echter, dit onderzoek richt zich specifiek op gepersonaliseerde cijfers over kanker, cijfers die dus beter bij uw situatie passen en u dus preciezer kunnen informeren. Het doel van dit onderzoek is om meer inzicht te krijgen in hoe dit soort gepersonaliseerde cijfers het beste gecommuniceerd kunnen worden richting patiënten.

U zult de twee verschillende prototypen doorlopen aan de hand van een vooraf gegeven scenario met kenmerken van patiënt X. Dit zijn dus niet uw eigen kenmerken. U dient zich in dit scenario in te leven, en de opdracht (die ook wordt gegeven) te doorlopen met de kenmerken van dit scenario. Erg belangrijk gedurende het doorlopen van de opdracht en het prototype is dat u al uw gedachtes hard op uitspreekt. U gaat dus hard op denken. Dit zal dadelijk nog wat beter worden uitgelegd. Zodra u het eerste prototype doorlopen hebt, zal er een korte pauze plaats vinden waarin u vragen kunt stellen als u die heeft en waarin ik of Ruben u kort om wat toelichting zal vragen mocht dit nodig zijn. Daarna doorloopt u nogmaals een prototype maar nu met een ander scenario. De ‘regels’ blijven verder wel hetzelfde. Zodra u ook hier mee klaar bent, zal er nog een interview plaats vinden waarin we nog wat dieper zullen in gaan op bepaalde gedachtes en voorkeuren die u had.

Belangrijk om te weten, is dat er geen verkeerde manier is om deze opdracht uit te voeren, niks is dus fout. U kunt alles zeggen wat er in uw gedachten naar boven komt, daarmee bevordert u dit onderzoek alleen maar meer. Er zijn geen stomme of rare gedachten. Daarnaast bent u volledig in het recht om te stoppen met dit onderzoek wanneer u dit zou willen zonder dat hier consequenties aan vast zitten. Mocht u zich om wat voor reden dan ook niet prettig meer voelen in dit onderzoek dan kunt u dus gelijk stoppen. (→ Consent formulier invullen).

Voor ik u beter ga uit leggen hoe het hardop denken precies in zijn werk gaat vraag ik u eerst om wat persoonlijke achtergrond gegevens in te vullen. (→ invullen achtergrond formulier)

Appendix F

Consent form

Patiënten informeren over overlevingscijfers bij kanker
Toestemmingsformulier

Uw deelname aan dit onderzoek is geheel vrijwillig. Tijdens het onderzoek heeft u het recht om u te allen tijde terug te trekken, om welke reden dan ook en zonder dat dit nadelige gevolgen heeft.

Als u deelname accepteert, geeft u aan:

- Dat u ouder bent dat 18 jaar;
- Dat u alle informatie heeft gelezen;
- Dat u de kans heeft gekregen om vragen te stellen over het onderzoek;
- Dat u ermee instemt dat uw stem mag worden opgenomen;
- Dat u ermee instemt dat de geanonimiseerde data tien jaar opgeslagen zullen worden;
- Dat u ermee instemt dat anonieme gegevens gebruikt kunnen worden voor verder wetenschappelijk onderzoek of wetenschappelijke publicaties;
- Dat u begrijpt dat anonieme gegevens niet gedeeld zullen worden met andere onderzoekers;
- Dat u begrijpt dat u zich te allen tijde en zonder opgeven van een reden terug mag trekken;
- Dat u begrijpt dat u uw gegevens zonder opgeven van een reden kunt laten verwijderen tot het moment van publicatie.

Antwoordopties:

☐ Ik geef toestemming, begin met het onderzoek
☐ Ik geef geen toestemming en wil niet meedoen met het onderzoek

Ondertekening deelnemer

Naam deelnemer: …………………………….………………………….

Handtekening deelnemer: …………………………….………………………….

Datum:
…………………………….………………………….

Ondertekening onderzoeker

Ik bevestig dat ik alle relevante informatie over de studie heb gegeven.

Naam onderzoeker: …………………………….………………………….

Handtekening onderzoeker: …………………………….………………………….

Datum: …………………………….………………………….

Appendix G

Background information form

Algemene vragenlijst

1. Vul hier de datum van vandaag in: ☐☐ / ☐☐ / 2 0 ☐☐

2. Vul hier uw geboortedatum in: ☐☐ / ☐☐ / 1 9 ☐☐

3. In welk jaar kreeg u de diagnose kanker?: ☐☐☐☐

4. Wat is uw geslacht?

☐ Man

☐ Vrouw

5. Wat is op dit moment uw burgerlijke status?

☐ Ik ben gehuwd

☐ Ik ben niet gehuwd, maar woon wel samen met mijn partner

☐ Ik heb een vaste partner, maar wij wonen apart

☐ Ik heb geen vaste partner

6. Heeft u kinderen? *(meerdere antwoorden mogelijk)*

☐ Nee, ik heb geen kinderen

☐ Ja, ik heb één of meer thuiswonende kinderen

☐ Ja, ik heb één of meer uitwonende kinderen

7. Kruis aan wat het hoogste niveau van opleiding is dat u heeft afgerond?

☐ Geen (of enkele klassen lager onderwijs)

☐ Basisschool

☐ Lager Beroeps Onderwijs (LBO)

☐ Middelbaar Algemeen Voortgezet Onderwijs (zoals MAVO, MULO)

☐ Middelbaar (beroeps-) onderwijs (MBO)

☐ Hoger Algemeen Voortgezet Onderwijs (zoals HAVO, Atheneum, Gymnasium)

☐ Hoger Beroeps Onderwijs (HBO)

☐ Wetenschappelijk (universitair) onderwijs

8. We zijn benieuwd naar uw huidige werksituatie *(meerdere antwoorden mogelijk)*

☐ Ik heb werk (betaald / onbetaald)

☐ Ik heb werk, maar maak volledig gebruik van de ziektewet

☐ Ik heb werk, maar maak gedeeltelijk gebruik van de ziektewet

☐ Ik heb geen werk

☐ Ik ben op zoek naar werk

☐ Ik ben student

☐ Ik ben huisvrouw / huisman

☐ Ik ben arbeidsongeschikt

☐ Ik ben gepensioneerd

☐ Anders, namelijk ☐

Appendix H

Semi-structured interview questions

Interview vragen [+ clustering categorie]
[Informatie]
[Gevoel]
[Lay-out]
[…] = afhankelijk van uitspraak

Pagina 1: introductie

- Was het duidelijk voor u wat het doel was van de website? [Informatie]
- Was de introductie informerend genoeg voor u? Voor beide versies? [Informatie]
- Wat vond u van de waarschuwingsteksten vooraf? [Gevoel]
- Was het duidelijk waarom deze waarschuwingsteksten getoond werden? Ja? Waarom dan? [Informatie]
- Kunt u mij vertellen welk gevoel er bij u naar boven kwam bij het lezen van deze waarschuwingsteksten? [Gevoel]

Pagina 2: keuze algemene vs. Gepersonaliseerde cijfers

- Was het verschil tussen algemene en gepersonaliseerde cijfers duidelijk voor u? Voor beide versies? [Informatie]

Pagina 3: invullen van persoonskenmerken

- Wat was uw algemene indruk over deze pagina? […]
- Was het duidelijk voor u waarom u de persoonskenmerken moest invoeren? Voor beide versies? [Informatie]
- Was het makkelijk voor u om de kenmerken in te voeren? [Lay-out]
- Kunt u mij iets meer vertellen over hoe u zich daar precies bij voelde? [Gevoel]
- Wat vond u prettig aan deze pagina? […]
- Wat vond u minder prettig aan deze pagina? […]
- Waren de teksten op deze pagina begrijpelijk? Voor beide versies? [Informatie]

Pagina 4: Invullen van ziektekenmerken

- Wat was uw algemene indruk over deze pagina? […]
- Was het duidelijk voor u waarom u kenmerken over de zieke moest invoeren? Voor beide versies? [Informatie]
- Was het makkelijk voor u om de kenmerken in te voeren? [Lay-out]
- Kunt u mij iets meer vertellen over hoe u zich daar precies bij voelde? [Gevoel]
- Wat vond u prettig aan deze pagina? […]
- Wat vond u minder prettig aan deze pagina? […]
- Waren de teksten op deze pagina begrijpelijk? Voor beide versies? [Informatie]

Pagina 5: resultaten

- Wat was uw algemene indruk over de resultatenpagina? […]

- Kunt u mij iets meer vertellen over hoe u zich voelde bij het zien van de resultaten? [Gevoel]
- Wat vond u prettig aan deze pagina? […]
- Wat vond u minder prettig aan deze pagina? […]
- Waren de teksten op deze pagina begrijpelijk? Voor beide versies? [Informatie]
- Waren de figuren op deze pagina begrijpelijk? Voor beide versies? [Informatie] [Lay-out]
- Vond u het fijn dat u controle had over het type figuur? [Lay-out]

Voorkeur voor presentatie format

- Heeft u een voorkeur voor één van de twee versies (de korte vs. de lange versie)? […]
- Kunt u mij vertellen waarom u een voorkeur heeft voor de korte of de lange versie? […]

Eigen gebruik

- Als de website online komt, zou u dan gebruik maken van deze tool? […]
- Waarom wel/waarom niet? […]

Overig

- Zijn er nog op- of aanmerkingen voor deze tool die we nog niet besproken hebben? […]

Appendix I

Debriefing

Hartelijk dank voor uw medewerking.

Wat wordt er getest in dit onderzoek?

Het doel van dit onderzoek is het verkrijgen van inzichten over hoe gepersonaliseerde getallen over kanker, zoals overlevingscijfers, het beste aangeboden kunnen worden richting patiënten. Hiervoor doorliep u een proefversie van een website waarbij de presentatie van de getallen centraal stond.

Tijdens het doorlopen van de webpagina’s moest u een aantal kenmerken invullen van een fictieve patiënt, en vroegen wij u om hardop uit de spreken waarom u sommige kenmerken wel/niet in wilden vullen en waarom u wel/niet klikte op bepaalde knoppen. We willen namelijk graag erachter zien te komen welke obstakels patiënten tegen kunnen komen bij het invullen van de kenmerken.

Daarnaast werden de resultaten op twee verschillende manieren gepresenteerd: (1) op een korte manier waarbij alleen de cijfers en paatjes werden getoond, en (2) op een uitgebreide manier waarbij de cijfers en plaatjes onderdeel waren van een verhaal en tevens werden ondersteund door toelichtende teksten. We zijn benieuwd hoe patiënten deze verschillende manieren beoordelen, en naar welke hun voorkeur uitgaat. Tot slot vroegen wij ons af of de presentatievoorkeur afhangt van of een patiënt een gunstig of een ongunstig overlevingscijfer krijgt aangeboden.

De getoonde overlevingscijfers op webpagina’s zijn door ons bedacht en dus onjuist.
Als u vragen hebt over het onderzoek, kunt u een e-mail sturen naar de hoofdonderzoeker,
Ruben Vromans ________________

Met vriendelijke groet,

Ruben Vromans
Onderzoeker Tilburg University & Integraal Kankercentrum Nederland (IKNL)